Compendium

of Health Related Quality of Life

Generic Instruments

Ergun Oksuz
Simten Malhan

Baskent University

ERGUN OKSUZ

SİMTEN MALHAN

COMPENDIUM OF HEALTH RELATED QUALITY OF LIFE

Generic Instruments

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Ankara - Turkey

The authors are
Ergun Oksuz (Family Physician, MD)
and **Simten Malhan** (PhD), Baskent University, Ankara Turkey

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Clifford Attkisson. University of California San Francisco, CA USA
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Per Bech. Frederiksborg General Hospital Hilleroed Denmark
Anja Berger. Robert Koch Institute Stresemannstr Berlin, Germany
Norman M. Bradburn. National Opinion Research Center University of Chicago USA
Robert H. Brook. RAND Health Communications, Santa Monica, CA USA
Bengt Brorsson. Swed. Council Tech. Assessment in Health Care Stockholm Sweden
Monica Bullinger. University of Hamburg, Hamburg Germany
Carol S. Burckhardt. Oregon Health Sciences University. Portland, OR USA
David R. Calkins. Harvard Medical School. Boston, MA USA
Charles S. Carver. Department of Psychology, University of Miami USA
Larry W. Chambers. Élisabeth Bruyère Research Institute. Ottawa Ontario Canada
Frank de Charro. Erasmus University Rotterdam The Netherlands
Paul D. Cleary. Yale School of Public Health, Yale University. New Haven, CT USA
Charles S. Cleeland. University of Texas MDA Cancer Center, Houston, TX USA
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J. Randall Curtis. University of Washington, Seattle, WA USA
Kristin M. David. University of California, San Diego, CA, USA
Allyson R. Davies. RAND Health Communications, Santa Monica, CA USA
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Arlene Fink. UCLA School of Public Health. Los Angeles, CA USA
Franco Franchignoni. Istituto Scientifico di Riabilitazione Veruno Italy
James F. Fries. Stanford University School of Medicine. Palo Alto, CA USA
William Bill Furlong. Coordinator, HUI Service Centre. Canada
Theodore G. Ganiats. University of California, San Diego, CA, USA
Thomas M. Gehring.University of Zürich Switzerland
Thomas K. Greenfield. University of California San Francisco, CA USA
Erik Groessl. University of California, San Diego, CA, USA
Alan W. Grogono. Tulane University School of Medicine, New Orleans, LA USA
Barry J Gurland. Columbia University Stroud Center New York, NY USA
Leona Hakkaart-van Roijen. Erasmus University Rotterdam. Netherlands
Jodi Harvey. University of California, San Diego La Jolla, CA USA
Graeme Hawthorne. The University of Melbourne, Parkville, Victoria, Australia
Michael E. Hyland. School of Psychology. University of Plymouth. UK.
Alan Jette. Boston University, Boston, MA USA
Jeffrey W. Jutai. University of Western Ontario London, ON Canada

Robert M. Kaplan. University of California, San Diego, CA, USA
GIJM (Ruud) Kempen. Faculty of Health Sciences, Maastricht University Netherlands
Rosemarie Kobau. Public Health Advisor. CDC, USA
Michelle Koch. QualityMetric Incorporated. Lincoln, RI USA
Jacqueline Kosecoff. University of California, Los Angeles, CA USA
Jeanne M. Landgraf. HealthAct. Boston, MA USA
Joelle Leacock. Boston University, Boston, MA USA
Debra Lerner. The Health Institute, New England Medical Center, Boston, MA USA
John M. Mayer. U.S. Spine& Sport Foundation. San Diego, CA USA
Diane Melendez. University of California San Francisco, CA USA
Joav Merrick. Ministry of Social Affairs Jerusalem, Israel
Elizabeth Russell-Minda. University of Western Ontario, London, ON Canada
Robb Most. President of Mind Garden, Inc. Redwood City, CA USA
George R Parkerson. Duke University Medical Center Durham, NC USA
Donald L. Patrick. University of Washington, USA
Rukmini Rajagopalan. Takeda Pharm. North America Inc. Lincolnshire IL USA
Ulrike Ravens-Sieberer. Robert Koch Institute Stresemannstr Berlin, Germany
Judy Rechsteiner. Stanford University School of Medicine. Palo Alto, CA USA
Margaret Reilly. Reilly Associates New York, NY USA
Lisa V. Rubenstein. School of Medicine University of California, Los Angeles CA US
Danny Ruta. Epidemiology and Public Health, University of Newcastle, UK
Jose Antonio Sacristan. Medical Director Eli Lilly, Madrid Spain
Marcia J. Scherer. University of Rochester Medical Center Rochester, NY USA
Surya Shah. Metropolitan University, Memphis, TN USA
William J. Sieber. University of California, San Diego, CA, USA
Johannes Siegrist. University of Düsseldorf Düsseldorf Germany
Stuart Silverman. Harvard Medical School Boston, MA USA
Harri Sintonen. Dept. of Public Health, University of Helsinki, Finland
Bernadette Ska. Montreal Geriatric University Institute. Montréal Quebec Canada
Elizabeth A. Skinner. Johns Hopkins Bloomberg Public Health Baltimore USA
Ernest Tani. National Opinion Research Center Chicago, IL USA
Dana Torres. RAND Health Communications, Santa Monica, CA USA
Ineke van Kempen. TNO Kwaliteit van Leven, Netherlands
Søren Ventegodt. Nordic School of Holistic Medicine, Copenhagen, Denmark
Kenneth A. Wallston. School of Nursing Vanderbilt University Nashville, TN USA
John H Wasson. Dartmouth Medical School Hanover, NH USA
Rhoda Weiss-Lambrou. Montreal University. Montréal Quebec Canada
David.J. Woodgate. St. Andrew's Hospital, Billericay, Essex UK
Roy T. Young. University of California, Los Angeles, CA USA

SUBMISSION

One of the most important indices of how well a country is doing developmentally is the "health" of that country. A healthy population usually produces a strong economy. Improving the health status of the country in general and the quality of life of persons in the population specifically are two of the goals of our country's health sector as well as of the World Health Organization.

Achieving this first requires actually determining the health of the country. Besides the indices of morbidity and mortality, other determinants are also important in assessing the actual health of a country. Quality-of-life measurements are a group of these determinants.

To improve a country's health, we first must understand and have a clear picture of its current state of health. Only then, can we build upon it and improve it. For this reason, 83 of the most widely used measurements in the literature, those that have a global impact, have been collected with the authors' permissions in this volume. This reference is being presented to healthcare professionals all over the world and contains the largest content in the literature to date. We at Baskent University hope that you will find it a useful tool to help you improve your country's health excellence.

All of Baskent University's sources are dedicated to positive sciences, and we continue to do our best to contribute to health sciences, both in Turkey as well as in the rest of the world.

It is my hope that this work will benefit all healthcare professionals seeking to attain the highest health status for their country and its population.

Sincerely,

Prof. Dr. Mehmet Haberal
President
Baskent University

SUBMISSION

Worldwide economic constraints on health care systems have emphasized stressed the need to monitor the outcomes of health care and the output of the systems.

In 1947 World Health Organization defined health as a state of complete physical, mental and social well-being. Aspects of any disease should be distunguished including pathology , morbidity functional impairment and associated handicap. Hovewer during the last few decades it became clear that the association between morbidity and health as defined above is seriously limited. Morbidity and functional impairment are only partially related to health outcomes. For evaluating health outcomes what we need is more knowledge and indicators. The quality of life measurement is one of the key indicator at this point. Quality of life studies have become important subject widely. Quality of life publishments percentage is 0.1% in 1980, 1.5 in 2004 among the whole cited publishes.

This is a reference book that provides in depth reviews of the quality of the leading health measurements. Although web-based information is increasingly becoming helpful, there are stil not enough written sources to evaluate health outcomes. Therefore in my opinion this reference book alternated to a compendium that covers 83 instruments. I believe that this compendium will have an important place in the literature.

I am aware that this publication should meet the information needs of many health and social researches, health service administrators, social workers and other health proffesionals. It is my earnest hope that it will lead to a greater use of sound concepts and up-to-date approaches to solving health problems and thereby make a significant contribution to progress towards the goal of health for all.

Prof. Dr. Korkut Ersoy
Baskent University
Vice President

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For a number of years we have been engaged in research in this area. These experiences have convinced us of the need for a book which covers QoL measurements in a way that would benefit those who plan to undertake such studies.

The measurements have been collected for three years. We hope that it meets the needs of wide readership that is envisaged.

We would like to thank our families for all the supports.

A number of sincer seniours have commented on an earlier draft of this book. They have investigated the book and commented on a particular sections. In all instances their comments have been constructive. We are grateful to Mithat Coruh, Barbaros Guncer, Nurhan Ozdemir and Bengu Capar for the comments received.

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Ergun Oksuz
& Simten Malhan
Baskent University
Ankara - Turkey

ABOUT COMPENDIUM

Quality of life (QOL) is a popular term describing one's overall sense of well-being and includes aspects of happiness and satisfaction with life as a whole. It is broad and subjective rather than specific and objective. The difficulty in measuring QOL lies in the fact that, although the term has meaning for nearly everyone and every academic discipline, this meaning varies among individuals and groups. At the same time, it is often used interchangeably with terms such as "health-related quality of life," "subjective health status," and "functional status," which are probably better descriptors of the instrument content. Such interchangeable use of terminology relates to the lack of a conceptual definition of quality of life or of subjective health status, even though most researchers agree that it is a multidimensional construct and that there are a variety of approaches by which it may be measured. The concept of subjective health status is, obviously, dependent on the patient's own opinion and definitions vary. Nevertheless, the content of some of the instruments is similar.

How do we reach accord about a measure for QOL? Perhaps the strongest area of a consensus is that QOL is extraordinarily broad and conceptually complex, yet measures are most meaningful when they incorporate key concepts in a logical way and are as precise as possible. Aspects of culture, values, and spirituality are key aspects of overall QOL that add to the complexity of its measurement. Although health is an important domain of overall QOL, there are other domains such as employment, housing, neighborhood, the quality of educational opportunities, and the whole external environment. Importantly, the external environment varies from culture to culture. QOL is affected by these external and internal factors. Nevertheless, psychology and sociology researchers have developed useful techniques that have helped to conceptualize and measure these multiple domains and how they relate to one another. We believe that every country should have their own national weights for using these techniques. You can find a detailed explanation in "Health Related Quality of Life" by Oksuz & Malhan (Baskent University Press).

What is health-related quality of life?

In 1948, after the World Health Organization defined health as "not only the absence of infirmity and disease but also a state of complete physical, mental, and social well being," physicians were reminded that a patient's health was more than just a corporeal state and that it could be affected by environmental and social factors. The subsequent appraisal of social and environmental factors was prompted not by medical researchers, but by major changes in government activities.

Although clinical measurements of functional status were often used for the elderly, clinicians and researchers paid little or no attention to early non-clinical publications by psychologists, which described surveys using indices to appraise happiness and psychological well-being. One study, in 1953, used objective measures that included good health, financial security, hobbies and interests, friends, living with one's spouse, age, and sex. Another study, in 1961, used subjective measures expressed as a life satisfaction scale and two smaller life satisfaction indexes. As a specific concept, the term "quality of life" (rather than quality of survival) seems to have entered the medical literature in a 1966 article about medically indigent patients receiving hemodialysis. After noting that the post dialysis medical problems included sepsis and cannula clotting, the authors concluded that, "while an effective degree of life prolongation was obtained for some of these patients, for most, the quality of life was unacceptable." QOL seems to have been judged from such events as difficulties finding a job, becoming too weak to care for children, and withdrawing from family. The authors also acknowledged that the problems, which had made all of the patients contemplate suicide, might have been improved with more suitable attention. In 1982, Johnson et al. adopted seven variables and the Affect Transformation Scale used by from previous social science publications. The research showed that patients with successful transplants had a better QOL than hemodialysis patients who were not awaiting transplantation or for whom transplantation was not planned or had already failed. Appraising the QOL results, the authors urged "continued efforts to apply social psychological research to clinical investigations...for evaluating medical interventions of many different kinds."

In 1984, Simmons et al., also appraising QOL in patients receiving hemodialysis, used a theoretical framework that combined physical, social, and emotional well-being, including the previously developed Index of Well-Being. This index as well as the Index of Psychological Affect and Index of Overall Life Satisfaction —all scales previously developed by Campbell, Converse, and Rodgers—were used by a nephrology group, led by R.W. Physicians also borrowed psychological tests from the social sciences, which were included in their battery of appraisals. Examples of such usages before 1984 include the following indexes: Rorschach test, Shanan Sentence Completion Technique, Psychosocial Adjustment to Illness Scale, Mooney Problem Checklist, Minnesota Multiphasic Personality Inventory, and Profile of Mood States. Other borrowed approaches included the use of sociologic guidelines for questionnaires and economic forms of utility analysis (in health services research). There was a relatively small but steady rise in the number of articles under the "quality of life" subject heading in Medline during 1975-1988. There was a sharp increase in 1989, which continued thereafter. From 2000 to 2006, there was an unbelievable jump in articles about QOL.

At the individual level, health-related quality of life (HRQOL) includes physical and mental health perceptions and their correlates, including health risks and conditions, functional status, social support, and socioeconomic status. However, some aspects of health do not appear to have a direct bearing on QOL at the time of assessment. These include an illness, exposure, or genetic predisposition that is not associated with symptoms and is unknown to the individual. HRQOL is rapidly gaining acceptance as a measurable outcome. HRQOL questions about perceived physical and mental health and function have become an important component of health surveillance and are generally considered to be valid indicators of service needs and intervention outcomes. Self-assessed health status has proven to be a more powerful predictor of mortality and morbidity than many objective measures of health. HRQOL measures make it possible to scientifically demonstrate the impact of QOL on health, going well beyond the old paradigm that was restricted to what could be seen under a microscope. In 1980, QOL studies confirmed findings from only 0.1% of all index studies. In 1990, this figure was 0.4%. In 2001, it was 0.9%, and in 2004, it was 1.5%. Most of these studies, which are descriptive cross-sectional and cohort studies, cover new measurements

and describe geographic and demographic or diagnosis criteria. Studies employing HRQOL measurements comprised 4.6% of all QOL studies in 1990, while in 2001 this percent increased to 12.6%. Although the number of published HRQOL studies accounts for an increasing percentage of general studies, these gains still fall short.

Can "health status" be measured?

It is intuitive that decisions as to how to use resources to improve health conditions, for society or for single individuals, will depend rather heavily of the way of measuring states of health. Clearly, it would be very helpful if a numerical measure of health was available so that "marginal health effect" of any given therapy might be computed as change in health per dollar (or YTL) spent in the treatment. As already mentioned, there are considerable difficulties connected with such a measurement. In Turkey, studies of health measurements have been poorly documented. There is no obvious unit of measurement for health, and even the concept of "health" as such is not clear. Most of the economics disciplines have run into similar difficulties, especially pharmacoeconomics or economics of drug treatment. As a consequence, reimbursement systems are used wastefully in Turkey. Even when seemingly exact measures exist, problems become apparent upon closer analysis (e.g., what does the GNP actually measure?). On the other hand, the analysis improves with more precise measures of the consequences of economic choices. Therefore, it is important to investigate how far one can go in measuring health. At a closer sight, this difficulty in measurement pervades all of health economics. At the outset, it obvious that there can be no measurement of health corresponding to those of the national accounts, where it makes sense to consider differences of two measured values as an expression of the magnitude of the improvement. However, one could still construct a suitable scale and position different health states on this scale in such a way that higher scale value corresponds to better health.

Despite the considerable obstacles that exist in measuring health, we believe that this compendium will be helpful to those interested in this subject. It covers 83 generic health measurements with their objectives, types, modes of administration, existing translation, conditions for use, weighting, score directions, and key references with abstracts.

Why measure impact?

Measuring the impact of an intervention helps people and organizations improve their plans, policies, and practices to ensure maximum benefit for the people and the communities, an outcome urgently needed in Turkey. Such measurements achieve these effects by doing the following:

- Demonstrating to ourselves and others how we make a difference
- Assessing whether what we do is effective in reaching our aims
- Acknowledging and sharing information about what has been less effective
- Providing feedback about knowledge and understanding of activities
- Creating transparency in what we do
- Gaining further funding and commitment for effective interventions
- Enabling those involved to share their experience and turn them into learning.

Who is it for?

This compendium is designed to enable and encourage practitioners to incorporate impact and effectiveness measures into their everyday work patterns. It is also designed to encourage more experienced practitioners to revisit the basics of evaluation. We recognise that time and money can restrict evaluations – this compendium serves as a reminder that measuring impact can be both simple and efficient. Practitioners who may find it useful include:

- Health planners and legislators
- Health policy makers
- Health improvement staff
- Project staff in healthy living centres
- Community development staff in statutory and voluntary sector organisations
- Researchers studying both health and social care
- Health professionals
- Private sector businesses

The success of HRQOL studies highly depends on the choice of an appropriate instrument. Instruments must be selected according to the domains they measure and the populations and pathologies for which they are designed. Practical issues such as the availability of different translations, copyright issues, and access to instruments are also major

factors affecting instrument choice. This compendium has been compiled based on these observations. This goal of this compendium is to provide all those involved in health care evaluation with a comprehensive and unique source of information on the available generic questionnaires.

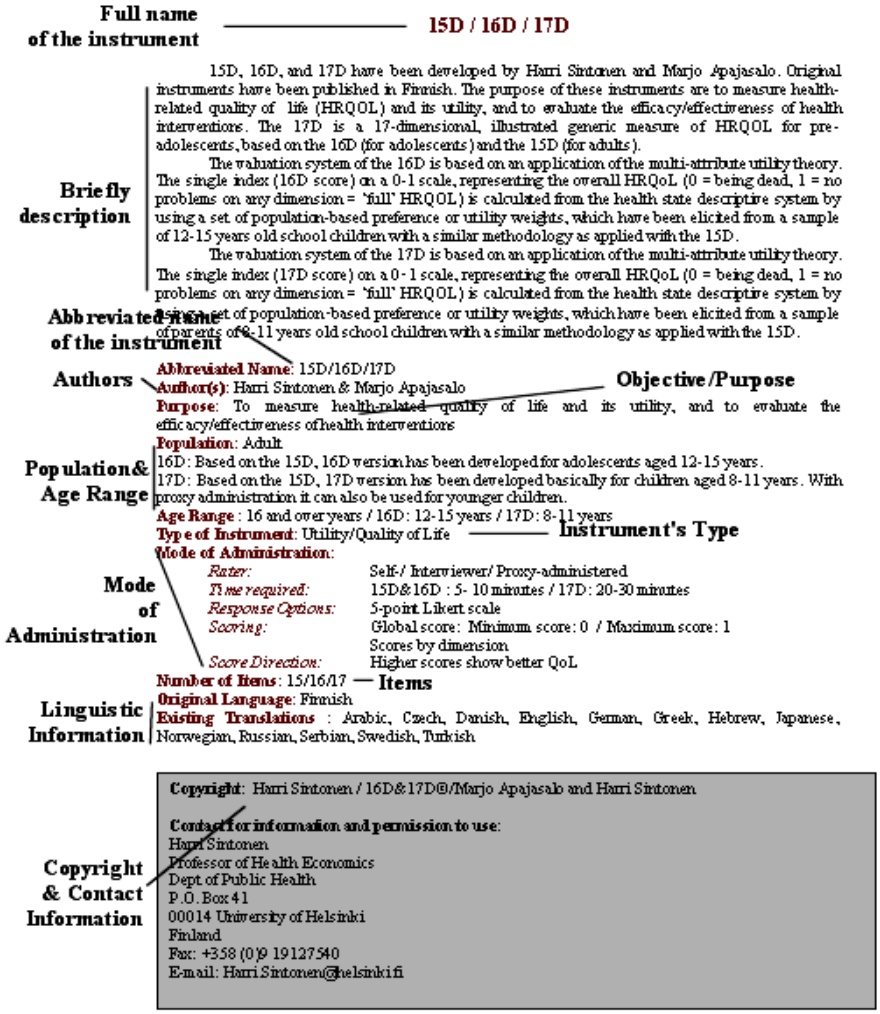
In Turkey, there is no compendium providing clear information on basic measurements. This compendium is intended to fill this gap. It is also expected to (1) aid researchers, who work in both health and social care, in measuring outcomes of service provision and interventions; (2) aid in the documentation of the impact of medical care on the quality and length of life of the population– especially given the rapid growth of the evidence for therapeutic efficacy among individual medical conditions; (3) help health planners and legislators allocate resources among competing health programs and to guide health policy by tracking important short- and long-term effects of health programs. This also may affect the pharmacoeconomics in Turkey. There are 83 generic instruments in this compendium. These measurements have been collected in three years by more than 80 authors. The measurements are collected from the literature, published studies, and the internet.

The compendium provides researchers with practical information on 83 generic QOL instruments including copies of all original questionnaires, dimensions covered by the questionnaires, translations, user manuals, contact and copyright information, detailed conditions of use, time for completion, and key bibliographic references (Figure 1).

The copyright of the instruments were either those of the authors or were taken from copyright holders listed in the compendium. HRQOL depends on the cultural subject. Accordingly, the reliability and validity of translations should be verified. Only under these conditions, where the instruments are proven to be reliable and valid, can they be used by researchers.

Researchers can also develop their own tools, while benefiting from the instruments in the compendium. Researchers should communicate with and get consents from authors or copyright holders before using instruments. This actual knowledge is served possibly in the related parts.

Figure 1: Current content and structure of information on 83 generic instruments



Dimensions covered by the questionnaire :

15D	16D	17D
▪ Mobility ▪ Vision ▪ Hearing ▪ Breathing ▪ Sleeping ▪ Eating ▪ Speech ▪ Elimination ▪ Usual Activities ▪ Mental function ▪ Discomfort and symptoms ▪ Depression ▪ Distress ▪ Vitality ▪ Sexual Activity	▪ Mobility ▪ Vision ▪ Hearing ▪ Breathing ▪ Sleeping ▪ Eating ▪ Speech ▪ Elimination ▪ School and hobbies ▪ Mental function ▪ Discomfort and symptoms ▪ Depression ▪ Distress ▪ Vitality ▪ Appearance ▪ Friends	▪ Mobility ▪ Vision ▪ Hearing ▪ Breathing ▪ Sleeping ▪ Eating ▪ Speech ▪ Elimination ▪ School and hobbies ▪ Learning and memory ▪ Discomfort and symptoms ▪ Depression ▪ Distress ▪ Vitality ▪ Appearance ▪ Friends ▪ Concentration

Dimensions /Domains

Each dimension contains 5 levels

Key References: ___ **Key Reference(s)**

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The objective of the study was to evaluate the reliability, validity and responsiveness of two generic multiattribute methods for measuring utility for health states: a 15-dimensional (15D) and a five-dimensional method (Euro Qol and EQ-TTO). A self-administered questionnaire with both measures was used in 59 outpatients with chronic obstructive pulmonary disease and the findings compared with standard gamble (SG) and time trade-off (TTO) utilities, spirometry and arterial blood gases. Quality of life scores were smallest for EQ-TTO (median 0.73) and highest for SG and TTO (median 0.91 and 0.95 respectively),

Copy/Sample of the Instrument

QUALITY OF LIFE QUESTIONNAIRE (15D©)

Please read through all the alternative responses to each question before placing a cross (x) against the alternative which best describes **your present health status**. Continue through all 15 questions in this manner, giving only **one** answer to each.

QUESTION 1. MOBILITY

1 ( ) I am able to walk normally (without difficulty) indoors, outdoors and on stairs.

2 ( ) I am able to walk without difficulty indoors, but outdoors and/or on stairs I have slight difficulties.

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15D / 16D / 17D

15D, 16D, and 17D have been developed by Harri Sintonen and Marjo Apajasalo. Original instruments have been published in Finnish. The purpose of these instruments are to measure health-related quality of life (HRQOL) and its utility, and to evaluate the efficacy/effectiveness of health interventions. The 17D is a 17-dimensional, illustrated generic measure of HRQOL for pre-adolescents, based on the 16D (for adolescents) and the 15D (for adults).

The valuation system of the 16D is based on an application of the multi-attribute utility theory. The single index (16D score) on a 0-1 scale, representing the overall HRQoL (0 = being dead, 1 = no problems on any dimension = 'full' HRQOL) is calculated from the health state descriptive system by using a set of population-based preference or utility weights, which have been elicited from a sample of 12-15 years old school children with a similar methodology as applied with the 15D.

The valuation system of the 17D is based on an application of the multi-attribute utility theory. The single index (17D score) on a 0‑1 scale, representing the overall HRQoL (0 = being dead, 1 = no problems on any dimension = 'full' HRQOL) is calculated from the health state descriptive system by using a set of population‑based preference or utility weights, which have been elicited from a sample of parents of 8-11 years old school children with a similar methodology as applied with the 15D.

Abbreviated Name: 15D/16D/17D
Author(s): Harri Sintonen & Marjo Apajasalo
Purpose: To measure health-related quality of life and its utility, and to evaluate the efficacy/effectiveness of health interventions
Population: Adult
16D: Based on the 15D, 16D version has been developed for adolescents aged 12-15 years.
17D: Based on the 15D, 17D version has been developed basically for children aged 8-11 years. With proxy administration it can also be used for younger children.
Age Range : 16 and over years / 16D: 12-15 years / 17D: 8-11 years
Type of Instrument: Utility/Quality of Life
Mode of Administration:

Rater:	Self-/ Interviewer/ Proxy-administered
Time required:	15D&16D : 5- 10 minutes / 17D: 20-30 minutes
Response Options:	5-point Likert scale
Scoring:	Global score: Minimum score: 0 / Maximum score: 1 Scores by dimension
Score Direction:	Higher scores show better QoL
Weighting:	Yes

Number of Items: 15/16/17
Original Language: Finnish
Existing Translations : Arabic, Czech, Danish, English, German, Greek, Hebrew, Japanese, Norwegian, Russian, Serbian, Swedish, Turkish

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Contact for information and permission to use:
Harri Sintonen
Professor of Health Economics
Dept of Public Health
P.O. Box 41
00014 University of Helsinki
Finland
Fax: +358 (0)9 19127540
E-mail: Harri.Sintonen@helsinki.fi

Dimensions covered by the questionnaire :

15D

- Mobility
- Vision
- Hearing
- Breathing
- Sleeping
- Eating
- Speech
- Elimination
- Usual Activities
- Mental function
- Discomfort and symptoms
- Depression
- Distress
- Vitality
- Sexual Activity

16D

- Mobility
- Vision
- Hearing
- Breathing
- Sleeping
- Eating
- Speech
- Elimination
- School and hobbies
- Mental function
- Discomfort and symptoms
- Depression
- Distress
- Vitality
- Appearance
- Friends

17D

- Mobility
- Vision
- Hearing
- Breathing
- Sleeping
- Eating
- Speech
- Elimination
- School and hobbies
- Learning and memory
- Discomfort and symptoms
- Depression
- Distress
- Vitality
- Appearance
- Friends
- Concentration

Each dimension contains 5 levels

Key References:

1. Stavem K. Reliability, validity and responsiveness of two multiattribute utility measures in patients with chronic obstructive pulmonary disease. Qual Life Res 1999; 8:45-54.

The objective of the study was to evaluate the reliability, validity and responsiveness of two generic multiattribute methods for measuring utility for health states: a 15-dimensional (15D) and a five-dimensional method (EuroQol and EQ-TTO). A self-administered questionnaire with both measures was used in 59 outpatients with chronic obstructive pulmonary disease and the findings compared with standard gamble (SG) and time trade-off (TTO) utilities, spirometry and arterial blood gases. Quality of life scores were smallest for EQ-TTO (median 0.73) and highest for SG and TTO (median 0.91 and 0.95 respectively), while 15D gave intermediate values (median 0.80). The test-retest reliability over 14 days was: 15D ($p = 0.90$) and EQ-TTO ($p = 0.73$), using Spearman's rank correlation. 15D was better than EQ-TTO at discriminating between groups of patients after reported global rating of change over 12 months ($P = 0.004$ versus $P = 0.09$), indicating that 15D was more responsive. The 15D instrument has many attractive properties when compared to the EQ-TTO method, including a better reliability and responsiveness. Validity depends on validation method. The findings in this study indicate that the different utility measures measure different aspects of health-related quality of life (HRQoL). Caution should be taken when choosing utility instruments in cost-utility studies, as this can strongly influence the results.

2. Sintonen H. The 15D instrument of health-related quality of life: properties and applications. Ann Med 2001; 33:328-36.

The 15D is a generic, comprehensive, 15-dimensional, standardized, self-administered measure of health-related quality of life (HRQoL) that can be used both as a profile and single index score measure. This paper examines the acceptability, reliability, validity, discriminatory power and responsiveness to change of its health state descriptive system and valuation system and presents some examples of applications. As a profile measure on roughly comparable dimensions the 15D performs equally well as the Nottingham Health Profile (NHP) and SF-20, in some respects even better, and clearly better than EQ-5D. The remaining nine to ten dimensions of the 15D provide a large reserve in terms of discriminatory power and responsiveness to change. The valuation system is based on an application of the multiattribute utility theory. The single index score (15D score) on a 0-1 scale, representing the overall HRQoL, is calculated from the health state descriptive system by using a set of population-based preference or utility weights. The 15D scores are shown to be highly reliable, sensitive and responsive to change, generalisable at least in Western-type societies, and particularly valid for deriving quality-adjusted life years (QALYs) gained for resource allocation purposes. The instrument is recommended by the Washington Panel and is available in several languages for clinical economic evaluation and population studies.

3. Hawthorne G, Richardson J, Day NA. A comparison of the Assessment of Quality of Life (AQoL) with four other generic utility instruments. Ann Med 2001; 33:358-70.

As part of the validation of the Assessment of Quality of Life (AQoL) instrument comparisons were made between five multiattribute utility (MAU) instruments, each purporting to measure health-related quality of life (HRQoL). These were the AQoL, the Canadian Health Utilities Index (HUI) 3, the Finnish 15D, the EQ-5D (formerly the EuroQoL) and the SF6D (derived from the SF-36). The paper compares absolute utility scores, instrument sensitivity, and incremental differences in measured utility between different instruments predicted by different individuals. The AQoL predicted utilities are similar to those from the HUI3 and EQ-5D. By contrast the 15D and SF6D predict systematically higher utilities, and the differences between individuals are significantly smaller. There is some evidence that the AQoL has greater sensitivity to health states than other instruments. It is concluded that at present no single MAU instrument can claim to be the 'gold standard', and that researchers should select an instrument sensitive to the health states they are investigating. Caution should be exercised in treating any of the instrument scores as representing a trade-off between length of life and HRQoL.

4. Sintonen H. The 15D-measure of health-related quality of life. I. Reliability, validity and sensitivity of its health state descriptive system. National Centre for Health Program Evaluation, Working Paper 41, Melbourne 1994

5. Sintonen H. The 15D-measure of health-related quality of life. II. Feasibility, reliability and validity of its valuation sys-tem. National Centre for Health Program Evaluation, Working Paper 42, Melbourne 1995

6. Apajasalo M, Rautonen J, Holmberg C, Sinkkonen J, Aalberg V, Pihko H, Siimes MA, Kaitila I, Mäkelä A, Erkkilä K, Sintonen H. Quality of life in pre-adolescence: A 17-dimensional health-related measure (17D). Quality of Life Research 5:1996; 532-538.

Although interest in the health-related quality of life (HRQOL) of children has increased in the last years, validated methods for assessing the HRQOL- and especially the perceived HRQOL-of children have been missing. We introduced a 17-dimensional, illustrated, generic measure of perceived HRQOL (17D) for pre-adolescents, and demonstrated its application to three populations of children aged 8-11 years: (1) 244 normal schoolchildren; (2) 22 patients surviving organ transplantation and (3) 10 patients with genetic skeletal dysplasias. The HRQOL scores and profiles of the patients differed significantly according to the diagnosis, giving support to its construct validity. The reliability of the measure was high: its repeatability coefficient was 95%. As a structured interview of 20-30 minutes, the measurement burden is reasonable. We conclude that the assessment of quality of life of pre-adolescents can and should be based on data collected from the children themselves. Our initial experience indicates that 17D is comprehensive, reliable, and valid.

7. Apajasalo M, Sintonen H, Holmberg C, Sinkkonen J, Aalberg V, Pihko H, Siimes MA, Kaitila I, Mäkelä A, Rantakari K, Anttila R, Rautonen J. Quality of life in early adolescence: A 16-dimensional health-related measure (16D). Quality of Life Research 5:1996; 205-211.

While data on the health-related quality of life (HRQOL) of adults are accumulating, very little is known about the HRQOL--and especially the perceived HRQOL--of children. In our study we introduced a 16-dimensional, generic self-assessment measure of HRQOL (16D) for early adolescents, and demonstrated its use with four populations of children aged 12-15: (1) 239 normal schoolchildren, (2) patients waiting for organ transplantation (n = 5), (3) patients with genetic skeletal dysplasias (n = 19), and (4) patients with epilepsy (n = 32). The HRQOL profiles of the patients differed significantly according to the diagnosis, giving support to its construct validity. The reliability of the measure was high: its repeatability coefficient was 91%. The quality of life ratings of the healthy boys and their parents differed on the dimensions of distress, vitality, speech, mental function, and discomfort and symptoms ($p < 0.05$). In addition, there were significant differences in the health-related valuations between the girls, boys and their parents. We conclude that the assessment of quality of life of adolescents should be based on data collected from the adolescents themselves. Further, the 16D is so far the only generic HRQOL measure designed specifically for this purpose. It is capable of differentiating the HRQOL of healthy adolescents as well as patients with various diagnoses. Our experience also indicates that it is easy to use, yet it seems comprehensive, reliable, and valid.

QUALITY OF LIFE QUESTIONNAIRE (15D©)

Please read through all the alternative responses to each question before placing a cross (x) against the alternative which best describes **your present health status**. Continue through all 15 questions in this manner, giving only **one** answer to each.

QUESTION 1. MOBILITY

1 ( ) I am able to walk normally (without difficulty) indoors, outdoors and on stairs.
2 ( ) I am able to walk without difficulty indoors, but outdoors and/or on stairs I have slight difficulties.
3 ( ) I am able to walk without help indoors (with or without an appliance), but outdoors and/or on stairs only with considerable difficulty or with help from others.
4 ( ) I am able to walk indoors only with help from others.
5 ( ) I am completely bed-ridden and unable to move about.

QUESTION 2. VISION

1 ( ) I see normally, i.e. I can read newspapers and TV text without difficulty (with or without glasses).
2 ( ) I can read papers and/or TV text with slight difficulty (with or without glasses).
3 ( ) I can read papers and/or TV text with considerable difficulty (with or without glasses).
4 ( ) I cannot read papers or TV text either with glasses or without, but I can see enough to walk about without guidance.
5 ( ) I cannot see enough to walk about without a guide, i.e. I am almost or completely blind.

QUESTION 3. HEARING

1 ( ) I can hear normally, i.e. normal speech (with or without a hearing aid).
2 ( ) I hear normal speech with a little difficulty.
3 ( ) I hear normal speech with considerable difficulty; in conversation I need voices to be louder than normal.
4 ( ) I hear even loud voices poorly; I am almost deaf.
5 ( ) I am completely deaf.

QUESTION 4. BREATHING

1 ( ) I am able to breathe normally, i.e. with no shortness of breath or other breathing difficulty.
2 ( ) I have shortness of breath during heavy work or sports, or when walking briskly on flat ground or slightly uphill.
3 ( ) I have shortness of breath when walking on flat ground at the same speed as others my age.
4 ( ) I get shortness of breath even after light activity, e.g. washing or dressing myself.
5 ( ) I have breathing difficulties almost all the time, even when resting.

QUESTION 5. SLEEPING

1 ( ) I am able to sleep normally, i.e. I have no problems with sleeping.
2 ( ) I have slight problems with sleeping, e.g. difficulty in falling asleep, or sometimes waking at night.
3 ( ) I have moderate problems with sleeping, e.g. disturbed sleep, or feeling I have not slept enough.
4 ( ) I have great problems with sleeping, e.g. having to use sleeping pills often or routinely, or usually waking at night and/or too early in the morning.
5 ( ) I suffer severe sleeplessness, e.g. sleep is almost impossible even with full use of sleeping pills, or staying awake most of the night.

QUESTION 6. EATING

1 ( ) I am able to eat normally, i.e. with no help from others.
2 ( ) I am able to eat by myself with minor difficulty (e.g. slowly, clumsily, shakily, or with special appliances).
3 ( ) I need some help from another person in eating.
4 ( ) I am unable to eat by myself at all, so I must be fed by another person.
5 ( ) I am unable to eat at all, so I am fed either by tube or intravenously.

QUESTION 7. SPEECH

1 ( ) I am able to speak normally, i.e. clearly, audibly and fluently.
2 ( ) I have slight speech difficulties, e.g. occasional fumbling for words, mumbling, or changes of pitch.
3 ( ) I can make myself understood, but my speech is e.g. disjointed, faltering, stuttering or stammering.
4 ( ) Most people have great difficulty understanding my speech.
5 ( ) I can only make myself understood by gestures.

QUESTION 8. ELIMINATION

1 ( ) My bladder and bowel work normally and without problems.
2 ( ) I have slight problems with my bladder and/or bowel function, e.g. difficulties with urination, or loose or hard bowels.
3 ( ) I have marked problems with my bladder and/or bowel function, e.g. occasional 'accidents', or severe constipation or diarrhea.
4 ( ) I have serious problems with my bladder and/or bowel function, e.g. routine 'accidents', or need of catheterization or enemas.
5 ( ) I have no control over my bladder and/or bowel function.

QUESTION 9. USUAL ACTIVITIES

1 ( ) I am able to perform my usual activities (e.g. employment, studying, housework, free-time activities) without difficulty.
2 ( ) I am able to perform my usual activities slightly less effectively or with minor difficulty.
3 ( ) I am able to perform my usual activities much less effectively, with considerable difficulty, or not completely.
4 ( ) I can only manage a small proportion of my previously usual activities.
5 ( ) I am unable to manage any of my previously usual activities.

QUESTION 10. MENTAL FUNCTION

1 ( ) I am able to think clearly and logically, and my memory functions well
2 ( ) I have slight difficulties in thinking clearly and logically, or my memory sometimes fails me.
3 ( ) I have marked difficulties in thinking clearly and logically, or my memory is somewhat impaired.
4 ( ) I have great difficulties in thinking clearly and logically, or my memory is seriously impaired.
5 ( ) I am permanently confused and disoriented in place and time.

QUESTION 11. DISCOMFORT AND SYMPTOMS

1 ( ) I have no physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
2 ( ) I have mild physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
3 ( ) I have marked physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
4 ( ) I have severe physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
5 ( ) I have unbearable physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.

QUESTION 12. DEPRESSION

1 ( ) I do not feel at all sad, melancholic or depressed.
2 ( ) I feel slightly sad, melancholic or depressed.
3 ( ) I feel moderately sad, melancholic or depressed.
4 ( ) I feel very sad, melancholic or depressed.
5 ( ) I feel extremely sad, melancholic or depressed.

QUESTION 13. DISTRESS

1 ( ) I do not feel at all anxious, stressed or nervous.
2 ( ) I feel slightly anxious, stressed or nervous.
3 ( ) I feel moderately anxious, stressed or nervous.
4 ( ) I feel very anxious, stressed or nervous.
5 ( ) I feel extremely anxious, stressed or nervous.

QUESTION 14. VITALITY

1 ( ) I feel healthy and energetic.
2 ( ) I feel slightly weary, tired or feeble.
3 ( ) I feel moderately weary, tired or feeble.
4 ( ) I feel very weary, tired or feeble, almost exhausted.
5 ( ) I feel extremely weary, tired or feeble, totally exhausted.

QUESTION 15. SEXUAL ACTIVITY

1 ( ) My state of health has no adverse effect on my sexual activity.
2 ( ) My state of health has a slight effect on my sexual activity.
3 ( ) My state of health has a considerable effect on my sexual activity.
4 ( ) My state of health makes sexual activity almost impossible.
5 ( ) My state of health makes sexual activity impossible.

QUALITY OF LIFE QUESTIONNAIRE (16D©)

Instructions:
This questionnaire is all about how you are right now. Please, read the questions carefully. Each question has five answers to choose from. Choose the answer that is closest to the way you are today and mark it with a cross (X).

Question 1
- ☐ I feel healthy and energetic
- ☐ I feel slightly weary, tired or weak
- ☐ I feel moderately weary, tired or weak
- ☐ I feel very weary, tired or weak
- ☐ I feel extremely weary, tired or weak

Question 2
- ☐ I can easily see words in books and TV text without glasses
- ☐ I can easily see words in books and TV text with glasses
- ☐ I cannot easily see words in books and TV text, even with glasses
- ☐ I cannot read books and TV text, even with glasses, but I can see well enough to walk without a guide
- ☐ I cannot see well enough to walk without a guide, i.e. I am almost or totally blind

Question 3
- ☐ I do not have any breathing problems
- ☐ I get breathless during heavy work or sports, or when walking fast on flat ground or slightly uphill (not the same as being out of breath after running)
- ☐ I get breathless when walking on flat ground
- ☐ I get breathless even with the lightest activity, e.g. washing or dressing myself
- ☐ I am breathless almost all the time, even when resting

Question 4
- ☐ I do not feel at all anxious, stressed or nervous
- ☐ I feel slightly anxious, stressed or nervous
- ☐ I feel moderately anxious, stressed or nervous
- ☐ I feel very anxious, stressed or nervous
- ☐ I feel extremely anxious, stressed or nervous

Question 5
- ☐ I hear normal speech well without a hearing aid
- ☐ I hear normal speech with slight difficulty, but I don't need a hearing aid
- ☐ I need a hearing aid, but I can hear well with it
- ☐ I hear poorly even with a hearing aid
- ☐ I am totally deaf

Question 6
- ☐ I have no problems with sleeping
- ☐ I have slight problems with sleeping, e.g. it is sometimes difficult to fall asleep, or I sometimes wake up at night
- ☐ I have moderate problems with sleeping, e.g. restless sleep, or feeling I have not slept enough
- ☐ I have great problems with sleeping, e.g. I have to take sleeping pills often or every night, or I usually wake at night or too early in the morning
- ☐ I find sleeping almost impossible, even with full use of sleeping pills, or I stay awake most of the night

Question 7
- ☐ I am able to eat without any difficulty
- ☐ I am able to eat with slight difficulty (e.g. slowly, clumsily or with special appliances)
- ☐ I need some help from another person in eating
- ☐ I am not able to feed myself at all, so I must be fed by someone else
- ☐ I am unable to eat at all, so I must be fed by tube or directly into my blood

Question 8
- ☐ I have no physical troubles or symptoms, e.g. pain, ache, feeling sick or itchy
- ☐ I have slight physical troubles or symptoms, e.g. pain, ache, feeling sick or itchy
- ☐ I have moderate physical troubles or symptoms, e.g. pain, ache, feeling sick or itchy
- ☐ I have severe physical troubles or symptoms, e.g. pain, ache, feeling sick or itchy
- ☐ I have unbearable physical troubles or symptoms, e.g. pain, ache, feeling sick or itchy

Question 9
- ☐ I am able to speak clearly, audibly and fluently
- ☐ I have slight difficulties with speaking, e.g. I sometimes stumble over words, or mumble, or my voice breaks
- ☐ I can make myself understood, but my speech is e.g. disjointed, faltering, stuttering or stammering.
- ☐ Most people have great difficulty understanding my speech
- ☐ I can only make myself understood by gestures

Question 10
- ☐ My weight, height and what I look like do not bother me
- ☐ My weight, height or what I look like bother me slightly
- ☐ My weight, height or what I look like bother me moderately
- ☐ My weight, height or what I look like bother me seriously
- ☐ My weight, height or what I look like bother me extremely

Question 11
- ☐ My state of health does not interfere with going to school or having hobbies
- ☐ My state of health makes it slightly difficult to go to school or have hobbies
- ☐ My state of health makes it moderately difficult to go to school or have hobbies
- ☐ My state of health makes it almost impossible to go to school or have hobbies
- ☐ My state of health makes it impossible to go to school or have hobbies

Question 12
- ☐ I can walk easily without an appliance (e.g. crutches or wheelchair)
- ☐ I have difficulty in walking, but I am able to walk without an appliance, e.g. crutches or wheelchair
- ☐ I cannot walk without an appliance, e.g. crutches or wheelchair, but with it I can move around well
- ☐ Moving around is very difficult, even with an appliance
- ☐ I cannot move around at all and I am bedridden

Question 13
- ☐ My state of health does not interfere with making friends or being with them
- ☐ My state of health makes it slightly difficult to make friends or be with them
- ☐ My state of health makes it moderately difficult to make friends or be with them
- ☐ My state of health makes it almost impossible to make friends or be with them
- ☐ My state of health makes it impossible to make friends or be with them

Question 14
- ☐ I am able to think clearly and logically
- ☐ I have slight problems in thinking clearly and logically
- ☐ I have moderate problems in thinking clearly and logically
- ☐ I have serious problems in thinking clearly and logically
- ☐ I am totally confused and unsure of the time and where I am

Question 15
- ☐ My bladder and bowels work normally
- ☐ I have a slight problem with my bladder or bowels, e.g. difficulties with urination, or hard or loose stools
- ☐ I have moderate problems with my bladder or bowels, e.g. occasional 'accidents', or bad constipation or diarrhoea
- ☐ I have serious problems with my bladder or bowels, e.g. frequent 'accidents', or need for enemas or catheters
- ☐ I have no control at all over my bladder or bowel functions

Question 16
- ☐ I do not feel at all sad, melancholic or depressed
- ☐ I feel slightly sad, melancholic or depressed
- ☐ I feel moderately sad, melancholic or depressed
- ☐ I feel very sad, melancholic or depressed
- ☐ I feel extremely sad, melancholic or depressed

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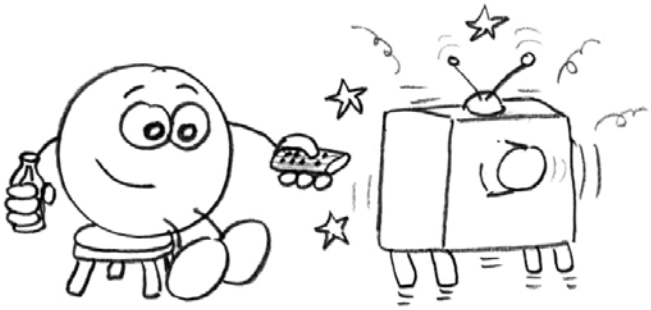
QUALITY OF LIFE QUESTIONNAIRE (17D©)

This questionnaire is all about how you are right now. Please, read the questions carefully. Each question has five answers to choose from. Choose the answer that is closest to the way you are today.

Question 1 is about how well you can see

How well can you see words in books and on the classroom board?



- ☐ Well, without glasses
- ☐ Well, with glasses
- ☐ Poorly, even with glasses
- ☐ I cannot see writing even with glasses, but I can see well enough to walk around without a guide
- ☐ I cannot see enough to walk around without a guide (I am almost or totally blind)

Question 2. How well can you hear?

- ☐ I can hear normal speech well without a hearing aid
- ☐ Normal speech is a bit difficult to hear, but I do not need a hearing aid
- ☐ I need a hearing aid, but I can hear well with it
- ☐ I hear poorly even with a hearing aid
- ☐ I am totally deaf

Question 3 is about moving around

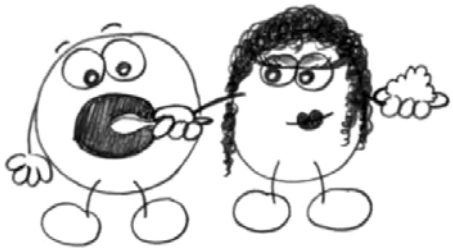
Can you walk without using an aid?

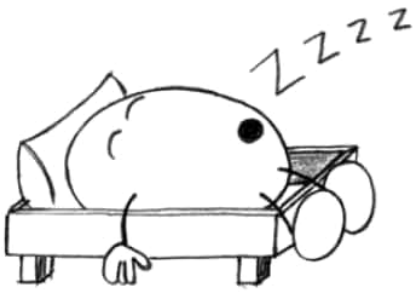
- ☐ Yes, without difficulty
- ☐ Yes, but walking is hard without an aid (like crutches or wheelchair)
- ☐ I cannot walk without an aid (like crutches or wheelchair), but with it I can move around well
- ☐ Moving around is hard even with an aid (like crutches or wheelchair)
- ☐ I cannot move around at all

Question 4.

Are you able to feed yourself?

- ☐ Yes, without any difficulty
- ☐ Yes, with a little difficulty (I am a bit slow, or clumsy, or I need a special aid, for example)
- ☐ Yes, if someone helps me a little all the time
- ☐ I cannot feed myself, so I must be fed by someone else
- ☐ I cannot eat at all, so I must be fed by tube or directly into my veins





Question 5.

How well do you sleep?

- ☐ I fall asleep easily and I sleep well
- ☐ It is sometimes hard to fall asleep, or I sometimes have nightmares or wake up at night
- ☐ It is often hard to fall sleep, or I often have nightmares or wake up at night
- ☐ It is nearly always hard to fall asleep, or I have nightmares or wake up almost every night
- ☐ I am awake most of the night

Question 6

Do you have any problems going to the toilet?

- ☐ No
- ☐ I have small problems (sometimes it takes a long time in the toilet, or I have to go often)
- ☐ I sometimes have 'accidents' (I mess or wet my trousers or bed), or I often get diarrhoea, or I can't go to the toilet for days
- ☐ I often have 'accidents', or I need a catheter or medicine to help me go to the toilet
- ☐ I nearly always mess or wet my trousers

Question 7

Everyone gets out of breath when they run fast, but do you otherwise get breathless or have other breathing problems?

- ☐ No
- ☐ Yes, when running slowly or walking fast
- ☐ Yes, when walking slowly
- ☐ Yes, even after light activity like washing or dressing myself
- ☐ Yes, almost all the time, even when resting

Question 8

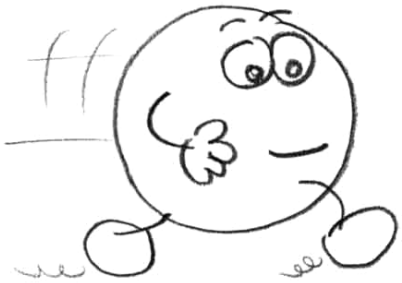
Do you have physical troubles or symptoms like pain, ache, feeling sick, or itchy?

- ☐ Not at all
- ☐ A little
- ☐ Quite a lot
- ☐ Very much
- ☐ It is unbearable

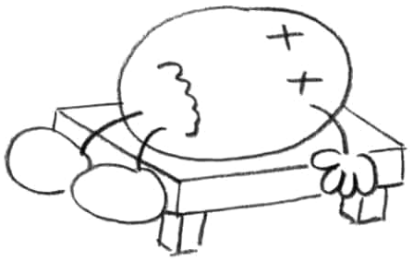
Question 9

People can feel healthy and energetic, or they can feel ill, tired and weak.

Do you feel



- ☐ healthy and energetic
- ☐ a little ill, tired or weak
- ☐ quite ill, tired or weak
- ☐ very ill, tired or weak
- ☐ extremely ill, tired or weak



Question 10

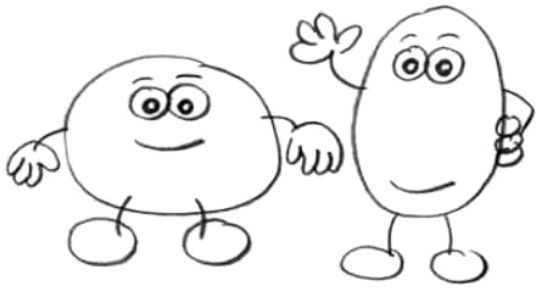
Do you feel scared or tense?

- ☐ Not at all
- ☐ A little scared or tense
- ☐ Quite scared or tense
- ☐ Very scared or tense
- ☐ Extremely scared or tense

Question 11

Are you happy with your weight, your height and how you look?

- ☐ I am completely happy
- ☐ I am quite happy
- ☐ I am rather unhappy
- ☐ I am very unhappy
- ☐ I am extremely unhappy



Question 12

Does your state of health make it difficult to go to school or have hobbies?

- ☐ Not at all
- ☐ A little (like not being able to do sports classes)
- ☐ Quite a lot (like I have difficulty walking or I miss school often because of sickness, or I am not able to have some hobbies)
- ☐ My state of health makes it almost impossible to go to school or have hobbies
- ☐ My state of health makes it impossible to go to school or have hobbies

Question 13

Does your state of health make it difficult to make friends or be with them?

- ☐ Not at all
- ☐ A little
- ☐ Quite a lot
- ☐ My state of health makes it almost impossible to make friends or be with them
- ☐ My state of health makes it impossible to make friends or be with them

Question 14

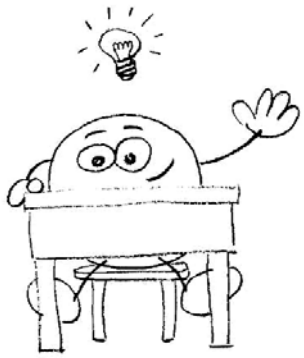
Sometimes it is hard to concentrate on the same thing for long, when thoughts jump from one thing to another

How long can you concentrate on the same thing?

- ☐ a long time
- ☐ quite a long time
- ☐ only a short time
- ☐ my thoughts are always jumping from one thing to another, and I can't really concentrate much
- ☐ I'm so restless that I can't concentrate for a moment

Question 15

How well can you learn new things and remember them?

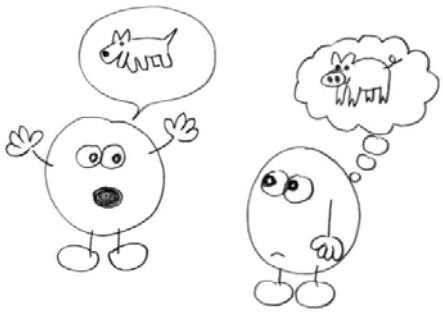


- ☐ I learn new things easily and remember them well
- ☐ It is a little hard for me to learn new things or remember them
- ☐ It is quite hard for me to learn new things or remember them
- ☐ It is very hard for me to learn new things or remember them
- ☐ I cannot learn or remember things

Question 16

How clearly can you speak?

- ☐ I can speak clearly
- ☐ It is a little hard for me to speak clearly
- ☐ It is quite hard for me to speak clearly
- ☐ Most people have difficulty understanding me when I speak
- ☐ I can only make myself understood with signing

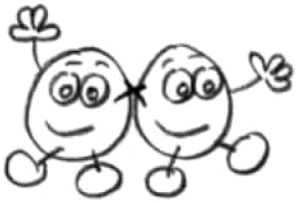


Question 17

People are not always cheerful and happy. Sometimes they can feel quite sad, unhappy and depressed.

Do you feel

- ☐ cheerful and happy
- ☐ a little sad, unhappy or depressed
- ☐ quite sad, unhappy or depressed
- ☐ very sad, unhappy or depressed
- ☐ extremely sad, unhappy or depressed



Thank you very much!

17D©/Marjo Apajasalo and Harri Sintonen

AFFECT BALANCE SCALE

The 10-item Affect Balance Scale has been developed by Norman Bradburn. Original instruments has been published in English. This measure of positive and negative feelings in the weeks before the interview provides an indication of the respondent's general psychological well-being. There are five positive items, which together form the Positive Affect subscale (PA-scale) and five negative items, which together form the Negative Affect subscale (NA-scale). The overall score on the scale is established by subtracting NA from PA.

Abbreviated Name: ABS
Author(s): Norman M. Bradburn
Purpose: To indicate the psychological reactions (positive or negative) of people in the general population to events in their daily life
Population: Adult
Age Range : 18 and over years
Type of Instrument: Psychosocial/ Psychological
Mode of Administration:

Rater:	Interviewer/ Self-administered
Time required:	5 to 10 minutes
Response Options:	Yes/No and Likert scale
Scoring:	Global score: There are two versions of the ABS, one using a Yes/No format which is scored from 0 to 10, and another one using a Likert scale format which is scored from 0 to 40.
Score Direction:	Higher scores show better QoL

Number of Items: 10
Original Language: English
Existing Translations : Cantonese, Spanish, Catalan, Dutch, French, German, Laotian, Vietnamese

Copyright: Bradburn, 1969

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Dimensions covered by the questionnaire :

- Positive Affects
- Negative Affects

Scoring : Positive affect questions receive a rating of 1 for yes and 0 for no. A Positive Affect Scale score is obtained by summing ratings for the five positive affect questions. Scores range from 0 to 5. A Negative Affect Scale score is obtained by summing the ratings for the five negative affect questions. Scores range from 0 to 5. The Affect Balance Scale score is computed by subtracting Negative Affect Scale scores from Positive Affect Scale scores and adding a constant of 5 to avoid negative scores. Scores range from 0 (lowest affect balance) to 10 (highest affect balance).
If the alternative format is used, responses are scored from 0 for "never" to 4 for "very often". Positive and Negative Scale Scores are computed similarly to method above. For the Affect Balance Scale a constant of 20 is added to avoid negative scores. The range can be from 0 to 40.

Key References:

1. Bradburn NM. The structure of psychological well-being. Chicago: Aldine Publishing Company; 1969:53-70.
2. Kempen GI. Psychometric properties of Bradburn's Affect Balance Scale among elderly persons. Psychological Reports 1992; 70: 638.

Some psychometric properties of the Affect Balance Scale have been tested on a random sample of 354 elderly people in the Netherlands. Internal reliability estimates were comparable with prior ones, and the 8-wk. test-retest reliability is reasonable for these 5-item measures.

3. Robinson JP, Shaver PR, Wrightsman LS, editors. Measures of personality and social psychological attitudes. San Diego: Academic Press; 1991.
4. Stacey CA, Gatz M. Cross-sectional age differences and longitudinal change on the Bradburn Affect Balance Scale. Journal of Gerontology 1991; 46(2): 76-78

Cross-sectional age differences and longitudinal change were examined on psychological well-being, positive affect, and negative affect, as measured by the Bradburn Affect Balance Scale. Data were collected from 1,159 participants in 1971 and 1985. Cross-sectional analyses showed age differences: older cohorts reported greater overall well-being but lower levels of both positive and negative affect when compared to younger respondents. Longitudinal analyses indicated small but significant changes toward decreased positive and negative affect but increased overall well-being. Negative affect had the strongest effect size. Positive and negative affect showed different patterns of change for different age groups. Taken together, cross-sectional and longitudinal findings suggest that change in affect variables is age-related, although these changes are relatively small. More evident was a pattern of correlational stability with age. Finally, the pattern of the results supports a two-factor theory of psychological well-being.

Affect Balance Scale

We are interested in the way people are feeling these days.
During the past few weeks, did you ever feel...

[Alternate wording: "how often did you feel...."]
[Please circle YES or NO following each description:]

(P) A. Particularly excited or interested in something? 1=YES 0=NO
(N) B. So restless that you couldn't sit long in a chair? 1=YES 0=NO
(P) C. Proud because someone complimented you on something you had done 1=YES 0=NO
(N) D. Very lonely or remote from other people? 1=YES 0=NO
(P) E. Pleased about having accomplished something? 1=YES 0=NO
(N) F. Bored? 1=YES 0=NO
(P) G. On top of the world? 1=YES 0=NO
(N) H. Depressed or very unhappy? 1=YES 0=NO
(P) I. That things were going your way? 1=YES 0=NO
(N) J. Upset because someone criticized you? 1=YES 0=NO

Note: (P) Positive Affect; (N) Negative Affect

ASSESSMENT OF QUALITY OF LIFE

Assessment Quality of Life (AQoL) has been developed by Graeme Hawthorne, Jeff Richardson & Richard Osborne. Original instrument has been published in English. The AQoL is an Australian-developed quality of life (QoL) instrument. It consists of 15-questions, organized into 5 scales, measuring Illness, Independence, Social Relationships, Physical Senses and Psychological Wellbeing. Scores from these five dimensions can be used to provide a QoL profile for respondents.

The main purpose of the AQoL, however, is to provide a QoL utility-index, and this is how most researchers have used the AQoL. When the AQoL utility score is being computed, the 3 three items from the Illness dimension are not included. Utility refers to the "value" of a quality of life state to the respondent. The utility values reported by the AQoL are scored on a life-death scale, where the lower boundary is –0.04 (representing QoL states worse than death), 0.00 (death equivalent QoL states) and to 1.00 (best possible QoL state). The utility weights used in scoring the AQoL are based on population values; it is the only utility instrument weighted with Australian values. When the reported utility index exists over time (eg a year), AQoL utilities are suitable for the calculation of quality-adjusted life years (QALYs) and the conduct of cost-utility analyses.

Abbreviated Name: AQoL
Author(s): Graeme Hawthorne, Jeff Richardson & Richard Osborne
Purpose: The AQoL is a multi-attribute utility measure for use in economic evaluation, measuring health-related quality of life. The descriptive system can be used to provide health profiles. There are two uses of the AQoL:

- It can be used to provide a quality of life profile describing a person's ability to live independently, to participate in a full social life, the level of their physical senses, their psychological wellbeing, and their health services use. If needed, the individual items can be presented giving a profile across 12 different aspects of life.
- It can also be used as a multi-attribute utility instrument for assessing the value of a person's quality of life through computing a weighted index, the utility score. The utility score is suitable for the calculation of quality-adjusted life years (QALYs) for use in economic evaluation, specifically cost-utility analysis.

Population: Adult
Age Range : 14 and over years
Type of Instrument: Utility/Quality of Life
Mode of Administration:

Rater:	Self-/ Interviewer/ Telephone-administered
Time required:	5-10 minutes
Response Options:	Guttman scales (On a life-death scale. 1.00 = equivalent full HRQoL; 0.00=equivalent death HRQoL; -0.04 = equivalent worse than death HRQoL.)
Scoring:	Global score
Score Direction:	Higher scores show better QoL
Weighting:	Yes

Number of Items: 15
Original Language: English
Existing Translations: Danish

For information on, or permission to use:

Contact for information and permission to use:

A/Professor Graeme Hawthorne
Department of Psychiatry,
The University of Melbourne,
Parkville,
Victoria, Australia, 3010
Email: graemeeh@unimelb.edu.au

Professor Jeff Richardson
Centre for Health Economics
Building 75
Monash University
Clayton Victoria 3800
AUSTRALIA

Dimensions covered by the questionnaire :

- Illness (medicine use, medical aids, medical treatment)
- Independent Living (self-care, daily activities, mobility)
- Social Relationships (intimacy, friends, family role)
- Physical Senses (vision, hearing, communication) and
- Psychological Wellbeing (sleep, anxiety, pain)

Key References:

1. Hawthorne G, Richardson J & Osborne R. (1999). The Assessment of Quality of Life (AQoL) instrument: a psychometric measure of health related quality of life. Quality of Life Research. 8: 209-224.

This paper describes constructing the Assessment of Quality of Life (AQoL) instrument; designed to measure health-related quality of life (HRQoL), and to be the descriptive system for a multi-attribute utility instrument. Unlike previous utility instruments' descriptive systems, the AQoL's has been developed using state-of-the-art psychometric procedures. The result is a descriptive system which emphasizes five different facets of HRQoL and which can claim to have construct validity. Based on the WHO's definition of health a model of HRQoL was developed. Items were written by focus groups of doctors and the researchers. These were administered to a construction sample, comprising hospital patients, and community members chosen at random. Final construction was through an iterative process of factor and reliability analyses. The AQoL measures 5 dimensions: illness, independent living, social relationships, physical senses and psychological wellbeing. Each has three items. Exploratory factor analysis showed the dimensions were orthogonal, and each was unidimensional. Internal consistency was alpha = 0.81. Structural equation modeling explored its internal structure; the comparative fit index was 0.90. These preliminary results indicate the AQoL has the prerequisite qualities for a psychometric HRQoL instrument for evaluation; replication with a larger sample is needed to verify these findings. Scaling it for economic evaluation using utilities is being undertaken. Respondents have indicated the AQoL is easy to understand and is quickly completed. Its initial properties suggest it may be widely applicable.

Scoring the AQoL

The AQoL can be scored in two ways:
• As a simple summative instrument where each dimension is reported as the sum of scores on the items within that dimension.
• As a multi-attribute utility (MAU) instrument, where a weighted multiplicative model is used to compute a utility score on a lifedeath scale.
o Only the last four dimensions of the AQoL are used in obtaining the utility score. Endorsed responses are substituted with values obtained from a stratified sample of the general Australian community using time trade-off (TTO; n = 225).
o Within each dimension, the three items are combined using a multiplicative model. Dimension scores are then
combined into a single index, again using a multiplicative model, and the resulting score is then transformed onto a life-death scale.
o The upper boundary, 1.00, represents the best HRQoL state, 0.00 represents HRQoL states that are death equivalent, and the lower boundary, -0.04, represents HRQoL states worse than death. HRQoL states worse
than death are necessary to explain people who have either committed suicide or euthanasia.

Applications of the AQoL

There are three applications for the AQOL. As a generic instrument, it is applicable to all public health and clinical conditions and interventions.
1. It can be used as a simple additive HRQoL measure, providing profile scores on independent living, social relationships, physical senses, and psychological wellbeing. Used like this, the AQOL can be used in program evaluation to assess the benefits associated with health interventions.
2. When utilities are computed, the AQOL can used as a HRQoL global index outcome measure in program evaluation to assess the benefits associated with health interventions.
3. When utilities are computed, the AQOL can used in economic evaluation, specifically in cost-utility analysis requiring the computation of quality-adjusted life years (QALYs). These evaluations may directly compare the cost-per-QALY gained between different health interventions for different health conditions, where the costutility analysis is intended to provide information assisting with decisions regarding resource allocation.

Reliability of the AQoL

Reliability has been assessed using internal consistency and test-retest.
• Based on community and hospital samples, the range of internal consistency estimates is Cronbach $\alpha = 0.73 – 0.84$.
• Based on a random community sample, two-week test-retest reliability was ICC = 0.83.
• Herrman et al reported a Pearson r = 0.55 of proxy (case manager) and self-completion by those suffering long–term psychosis; and suggested that self-completion was to be preferred.

Normative data

The general population norm for the AQoL utility, based on the 1998 South Australian Health Omnibus Survey (n = 3000 adults) is 0.83 (sd = 0.20), the range was from 0.66 through to 0.88 depending upon gender and age group. A smaller stratified sample of the Victorian population (n = 334) provided estimates from 0.71–0.84, depending upon age group.

Clinical data

There are a limited number of published papers on the AQoL in clinical settings, mainly because it is a relatively new measure.
Studies include Alzheimer's disease, cochlear implants, influenza, nutrition, osteoarthritis, post-acute discharge care, pharmacist medication, psychosis, and stroke.

Public health data

There are a limited number of published papers on the AQoL in public health settings, mainly because it is a relatively new measure.
Studies include: aged care, coordinated care, depression, incontinence, obesity, osteoarthritis, substance abuse, suicidal ideation, trauma and willingness to pay.

ASSESSMENT OF QUALITY OF LIFE (AQOL)[1]

INSTRUCTIONS:

Please circle the alternative that best describes you *during the last week*.

1 Concerning my use of prescribed medicines:
- A. I do not or rarely use any medicines at all.
- B. I use one or two medicinal drugs regularly.
- C. I need to use three or four medicinal drugs regularly.
- D. I use five or more medicinal drugs regularly.

2 To what extent do I rely on medicines or a medical aid? (NOT glasses or a hearing aid.)
(For example: walking frame, wheelchair, prosthesis etc.)
- A. I do not use any medicines and/or medical aids.
- B. I occasionally use medicines and/or medical aids.
- C. I regularly use medicines and/or medical aids.
- D. I have to constantly take medicines or use a medical aid.

3 Do I need regular medical treatment from a doctor or other health professional?
- A. I do not need regular medical treatment.
- B. Although I have some regular medical treatment, I am not dependent on this.
- C. I am dependent on having regular medical treatment.
- D. My life is dependent upon regular medical treatment.

4 Do I need any help looking after myself?
- A. I need no help at all.
- B. Occasionally I need some help with personal care tasks.
- C. I need help with the more difficult personal care tasks.
- D. I need daily help with most or all personal care tasks.

5 When doing household tasks: *(For example, preparing food, gardening, using the video recorder, radio, telephone or washing the car)*
- A. I need no help at all.
- B. Occasionally I need some help with household tasks.
- C. I need help with the more difficult household tasks.
- D. I need daily help with most or all household tasks.

6 Thinking about how easily I can get around my home and community:
- A. I get around my home and community by myself without any difficulty.
- B. I find it difficult to get around my home and community by myself.
- C. I cannot get around the community by myself, but I can get around my home with some difficulty.
- D. I cannot get around either the community or my home by myself.

7 Because of my health, my relationships (eg: with my friends, partner or parents) generally:
- A. Are very close and warm.
- B. Are sometimes close and warm.
- C. Are seldom close and warm.
- D. I have no close and warm relationships.

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[1] Hawthorne & Richardson (1996) © All rights reserved. *Assessment of Quality of Life (AQoL)* instrument. Melbourne, Centre for Health Program Evaluation. The AQoL may not be copied or used without permission.

8 Thinking about my relationship with other people:
- A. I have plenty of friends, and am never lonely.
- B. Although I have friends, I am occasionally lonely.
- C. I have some friends, but am often lonely for company.
- D. I am socially isolated and feel lonely.

9 Thinking about my health and my relationship with my family:
- A. My role in the family is unaffected by my health.
- B. There are some parts of my family role I cannot carry out.
- C. There are many parts of my family role I cannot carry out.
- D. I cannot carry out any part of my family role.

10 Thinking about my vision, including when using my glasses or contact lenses if needed:
- A. I see normally.
- B. I have some difficulty focusing on things, or I do not see them sharply. *For example: small print, a newspaper, or seeing objects in the distance.*
- C. I have a lot of difficulty seeing things. My vision is blurred. *For* example: I can see just enough to get by with.
- D. I only see general shapes, or am blind. *For example: I need a guide to move around.*

11 Thinking about my hearing, including using my hearing aid if needed:
- A. I hear normally.
- B. I have some difficulty hearing or I do not hear clearly. *For example: I ask people to speak up, or turn up the TV or radio volume.*
- C. I have difficulty hearing things clearly. *For example: Often I do not understand what is said. I usually do not take part in conversations because I cannot hear what is said.*
- D. I hear very little indeed. *For example: I cannot fully understand loud voices speaking directly to me.*

12 When I communicate with others: *(For example: by talking, listening, writing or signing)*
- A. I have no trouble speaking to them or understanding what they are saying.
- B. I have some difficulty being understood by people who do not know me. I have no trouble understanding what others are saying to me.
- C. I am only understood by people who know me well. I have great trouble understanding what others are saying to me.
- D. I cannot adequately communicate with others.

13 If I think about how I sleep:
- A. I am able to sleep without difficulty most of the time.
- B. My sleep is interrupted some of the time, but I am usually able to go back to sleep without difficulty.
- C. My sleep is interrupted most nights, but I am usually able to go back to sleep without difficulty.
- D. I sleep in short bursts only. I am awake most of the night.

14 Thinking about how I generally feel:
- A. I do not feel anxious, worried or depressed.
- B. I am slightly anxious, worried or depressed.
- C. I feel moderately anxious, worried or depressed.
- D. I am extremely anxious, worried or depressed.

15 How much pain or discomfort do I experience?
- A. None at all.
- B. I have moderate pain.
- C. I suffer from severe pain.
- D. I suffer unbearable pain.

AQOL-2[1]

Dimension 1: Independent living

Q1 How much help do I need with household tasks: (E.g. preparing food, cleaning the house or gardening.)

- ❑ I can do all these tasks very quickly and efficiently without any help
- ❑ I can do these tasks relatively easily without help
- ❑ I can do these tasks only very slowly without help
- ❑ I cannot do most of these tasks unless I have help
- ❑ I can do none of these tasks by myself.

Q2 Thinking about how easy or difficult it is for me to get around by myself outside my house (eg shopping, visiting):

- ❑ getting around is enjoyable and easy
- ❑ I have no difficulty getting around outside my house
- ❑ a little difficulty
- ❑ moderate difficulty
- ❑ a lot of difficulty
- ❑ I cannot get around unless somebody is there to help me.

Q3 Thinking about how well I can walk.

- ❑ I find walking or running very easy
- ❑ I have no real difficulty with walking or running
- ❑ I find walking or running slightly difficult. I cannot run to catch a tram or train, I find walking uphill difficult
- ❑ walking is difficult for me. I walk short distances only, I have difficulty walking up stairs
- ❑ I have great difficulty walking. I cannot walk without a walking stick or frame, or someone to help me
- ❑ I am bedridden.

Q4 Thinking about washing myself, toileting, dressing, eating or looking after my appearance:

- ❑ these tasks are very easy for me
- ❑ I have no real difficulty in carrying out these tasks
- ❑ I find some of these tasks difficult, but I manage to do them on my own
- ❑ many of these tasks are difficult, and I need help to do them
- ❑ I cannot do these tasks by myself at all.

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[1] Richardson J, Hawthorne G, Day N, Peacock S (2003) © All rights reserved. The *Assessment of Quality of Life Version 2* (AQoL-2) instrument may not be copied, used or modified without permission.

Dimension 2: Social Dimension

Q5 My close and intimate relationships (including any sexual relationships) make me:

- ❑ very happy
- ❑ generally happy
- ❑ neither happy nor unhappy
- ❑ generally unhappy
- ❑ very unhappy

Q6 Thinking about my health and my relationship with my family:

- ❑ my role in the family is unaffected by my health
- ❑ there are some parts of my family role I cannot carry out
- ❑ there are many parts of my family role I cannot carry out
- ❑ I cannot carry out any part of my family role.

Q7 Thinking about my health and my role in my community (that is to say neighbourhood, sporting, work, church or cultural groups):

- ❑ my role in the community is unaffected by my health
- ❑ there are some parts of my community role I cannot carry out
- ❑ there are many parts of my community role I cannot carry out
- ❑ I cannot carry out any part of my community role.

Dimension 3: Mental Health

Q8 How often did I feel in despair over the last seven days?

- ❑ never
- ❑ occasionally
- ❑ sometimes
- ❑ often
- ❑ all the time.

Q9 And still thinking about the last seven days: how often did I feel worried:

- ❑ never
- ❑ occasionally
- ❑ sometimes
- ❑ often
- ❑ all the time.

Q10 How often do I feel sad?

- ❑ never
- ❑ rarely
- ❑ some of the time
- ❑ usually
- ❑ nearly all the time.

Q11 When I think about whether I am calm and tranquil or agitated, I am:

- ❑ always calm and tranquil
- ❑ usually calm and tranquil
- ❑ sometimes calm and tranquil, sometimes agitated
- ❑ usually agitated
- ❑ always agitated.

Dimension 4: Coping

Q12 Thinking about how much energy I have to do the things I want to do, I am:

- ❑ always full of energy
- ❑ usually full of energy
- ❑ occasionally energetic
- ❑ usually tired and lacking energy
- ❑ always tired and lacking energy.

Q13 How often do I feel in control of my life?

- ❑ always
- ❑ mostly
- ❑ sometimes
- ❑ only occasionally
- ❑ never.

Q14 How much do I feel I can cope with life's problems?

- ❑ completely
- ❑ mostly
- ❑ partly
- ❑ very little
- ❑ not at all.

Dimension 5 Pain

Q15 Thinking about how often I experience serious pain. I experience it:

- ❑ very rarely
- ❑ less than once a week
- ❑ three to four times a week
- ❑ most of the time.

Q16 How much pain or discomfort do I experience:

- ❑ none at all
- ❑ I have moderate pain
- ❑ I suffer from severe pain
- ❑ I suffer unbearable pain

Q17 How often does pain interfere with my usual activities?

- ❑ never
- ❑ rarely
- ❑ sometimes
- ❑ often
- ❑ always.

Dimension 6: Sensory Perception

Q18 Thinking about my vision (using my glasses or contact lenses if needed):

- ❑ I have excellent sight
- ❑ I see normally
- ❑ I have some difficulty focusing on things, or I do not see them sharply. E.g. small print, a newspaper or seeing objects in the distance.
- ❑ I have a lot of difficulty seeing things. My vision is blurred. I can see just enough to get by with.
- ❑ I only see general shapes. I need a guide to move around
- ❑ I am completely blind.

Q19 Thinking about my hearing (using my hearing aid if needed)

- ❑ I have excellent hearing
- ❑ I hear normally
- ❑ I have some difficulty hearing or I do not hear clearly. I have trouble hearing softly-spoken people or when there is background noise.
- ❑ I have difficulty hearing things clearly. Often I do not understand what is said. I usually do not take part in conversations because I cannot hear what is said.
- ❑ I hear very little indeed. I cannot fully understand loud voices speaking directly to me.
- ❑ I am completely deaf.

Q20 When I communicate with others, e.g. by talking, listening, writing or signing:

- ❑ I have no trouble speaking to them or understanding what they are saying
- ❑ I have some difficulty being understood by people who do not know me. I have no trouble understanding what others are saying to me.
- ❑ I am understood only by people who know me well. I have great trouble understanding what others are saying to me.
- ❑ I cannot adequately communicate with others.

ASSISTIVE TECHNOLOGY DEVICE PREDISPOSITION ASSESSMENT

Assistive Technology Device Predisposition Assessment has been developed by Marcia Scherer and is the intellectual property of her institution, Institute for Matching Person&Technology. Original instruments has been published in English. The Assistive Technology Device Predisposition Assessment collects information on physical capabilities, life satisfaction, feelings about having a disability, and temperament.

The Institute for Matching Person & Technology was formed to better match users of technologies with the most appropriate devices for their use. The Institute works to enhance the situation of technology users through research, assessment, training and consultation.

- Do you know persons who avoid the use of technologies? Persons who have abandoned them? Do you want to prevent or minimize this in the future?
- Do you worry that you haven't considered all the important factors affecting a person's optimal technology use?
- Do you wonder if technology use will really result in an improved situation?

Technologies are meant to make our lives easier and better. Unfortunately, it doesn't always work out this way. It is important that individuals feel comfortable with technologies and know how to use them to their benefit. While a user must adapt to the unique features and demands of a technology, a technology must be adjusted or adapted to accommodate the individual needs and preferences of the user. This is true regardless of the type of technology:

Assistive Technologies – products for persons with physical disabilities designed to enhance independence and functioning (examples are wheelchairs, adapted utensils, communication devices).

Educational Technologies - used to help students learn in classroom settings or at a distance (examples are multimedia delivery systems, self-instructional software programs).

Workplace Technologies - designed to enhance job performance and productivity through multi-tasking, networking, telecommuting, and so on (examples are electronic scheduling devices, telecommunications software).

and General, Everyday, Technologies to make our daily activities easier, more efficient and pleasurable (examples include automatic (bank) teller machines, VCR's).

The Matching Person and Technology (MPT) assessment process is one means for providing a more personal approach to matching person and technology.

Abbreviated Name: ATD-PA
Author(s): Marcia J. Scherer
Purpose: To evaluate predispositions to and outcomes of technology use in rehabilitation, education, the workplace and other settings
Population: Adult/ A version for children is also available: Matching Assistive Technology and Child (MATCH)
Age Range: 18 - 99 years
Type of Instrument: Disability/Physical functioning / Quality of Life / Social functioning / Coping / Psychosocial/Psychological
Mode of Administration:

Rater:	Self- / Interviewer-/ Telephone administered
Time required:	20 minutes
Response Options:	Yes/No - 5 point-Likert scale
Scoring:	Scores by dimension
Score Direction:	Higher scores show better QoL
Weighting:	Yes

Number of Items: 63
Original Language: English
Existing Translations : French, Italian.

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Contact for information and permission to use:

Marcia J. Scherer, PhD., MPH,
Associate Professor of Physical Medicine and Rehabilitation
University of Rochester Medical Center
601 Elmwood Ave., P.O. Box 664
Rochester, NY 14642 USA
Phone/Fax: +1 (585) 671-3461
E-mail: marcia_scherer@urmc.rochester.edu
E-mail: IMPT97@aol.com

Dimensions covered by the questionnaire :

- Disability/physical functioning (9 items)
- Psychosocial/Psychological, Coping (33 items)
- Quality of life, Satisfaction, Social functioning (11 items)

Key References:

1. Scherer MJ. Connecting to Learn: Educational and Assistive Technologies for People with Disabilities. Washington, DC: American Psychological Association (APA) Books. 2004

Development and validation of the MPT assessments followed the recommended steps for test/measure construction as follows: (1) concept definition and clarification, (2) draft of items and response scales, (3) pilot testing, and (4) determination of measure quality and usefulness (Scherer, 1995).
Studies related to the psychometric properties of the ATD PA and ET PA, which are of most relevance to the content of this book include the following:
Inter-rater Reliability. Thirty rehabilitation professionals or graduate students rated videotaped interviews, supplemented with written information, of individuals using Assistive or educational technologies. Item modes were calculated and the differences between the mode and individual rater responses were computed. The items related to the technology itself and its use within the family or workplace received the highest consistency in ratings. Items concerned with user characteristics and whether each was an incentive or disincentive to technology use had less consistent agreement (Scherer & McKee, 1992).
Scherer & Cushman (2001) studied twenty persons with newly acquired SCI (10 males and 10 females) who completed items from (a) Section B of the ATD PA hypothesized to assess QOL, (b) the Satisfaction with Life Scale (SWLS), and (c) Brief Symptom Inventory (BSI) while in acute rehabilitation. One month post-discharge, subjects rated their assistive technology satisfaction.
Concurrent validity of the ATD PA's QOL scale with the SWLS and *construct validity* with the BSI depression subscale was assessed using Spearman correlations. All items on both the SWLS and QOL subset correlate negatively with the BSI depression subscale. The QOL scale total score and SWLS total score correlated very highly (.89, $p<.01$) which suggests that they measure the same construct, in this case quality of life.
Fourteen consumers provided data on their AT satisfaction at 1-month post acute rehabilitation. Nine (64.3%) of the respondents indicated they were Satisfied with their AT and 5 (35.7%) reported being Not Satisfied with their AT. An independent-samples t test was used to evaluate the hypothesis that the QOL scale of the ATD PA would better discriminate (*predictive validity*) between the two groups than Diener's SWLS. The depression subscale of the BSI was not tested because of its low correlation with AT

satisfaction (-.04). Persons not satisfied with their AT (mean = 23.20, SD = 7.59) on average scored lower on the QOL scale than those satisfied with their AT (mean = 34.56, SD = 9.27). The effect size was estimated with the eta square index (.34) indicating a large effect size (an alternate way of presenting this statistic is to say that 34% of the variance in the modified QOL subset was accounted for by whether a person was satisfied or not satisfied with their AT 1-month post-discharge).

Item analyses were conducted on the ATD PA scale hypothesized to assess QOL to determine *internal consistency*. Initially, each item was correlated with the total score for QOL (with the item removed). All items were retained in the analysis and coefficient alpha for the QOL subset was .80, which is high. In Ireland, the QOL scale also has been determined to have high internal consistency with a coefficient alpha above .80. The Ireland assessment combined items from the SOTU, ATD PA and ET PA. In their study of technology needs and preferences of students with disabilities (including many with hearing or eyesight loss) transitioning from secondary education to employment or university, a scale to measure Learner Self Esteem and Autonomy has been found to have high internal consistency with a coefficient alpha above .80 (Scherer & Cradock, 2002). Data on the validity of the MPT process and assessments in a consumer and peer provider partnership approach to technology selection, training and outcomes is an on-going focus of the pioneering model of service delivery being used now in Ireland (Craddock, 2002; Craddock & McCormack, 2002). A similar model using peer mentors in a New York State Tech Act project used the MPT assessments to help consumers identify the best technologies for their use (Heerkens, Briggs & Weider, 1997).

Criterion-Related Validity. Older adults (mean age 65) with normal hearing and comparably aged users of assistive listening devices or ALDs completed the following measures: (a) Hearing Handicap Inventory for the Elderly, (b) The Communication Profile for the Hearing Impaired (CPHI), and (c) the ATD PA. Parts of both the CPHI and the ATD PA produced significant mean differences between ALD users and non-users, suggesting the value of assessing personality and psychosocial factors involved in technology use [9]. Users in general attribute more value to ALDs, have higher psychological readiness for adopting technical assistance, and perceive fewer difficulties with technology use around family, friends, at work or school than do non-users. Then, behavioral and audiological data were obtained from 40 subjects 61-81 years of age. Group A included 20 subjects with normal audiological thresholds. Group B included 20 subjects with mild-to-moderate degrees of high-frequency hearing loss. Each subject completed a hearing loss screening survey, ATD PA and Profile of Hearing Aid Performance (PHAP). The PHAP and hearing loss screen were adequate assessments of self-reported hearing loss, as was the subjective rating of hearing section of the ATD PA. People with high-frequency marginal hearing loss reported less satisfaction with their independence, reduced emotional well-being, and more limitation from their hearing loss than those with normal hearing. Discriminant analyses showed that the ATD PA was the best predictor of membership in Group A or Group B, correctly classifying 85 percent of the participants and providing psychosocial markers associated with awareness of and adaptation to hearing loss (Scherer & Frisina, 1994; Scherer & Frisina, 1998).

Predictive Validity. To determine the usefulness of the ATD PA in determining reasons for device nonuse or abandonment, 47 persons with mixed diagnoses discharged from an acute inpatient rehabilitation unit completed the instrument at the time of discharge and at 3-months postdischarge. Their occupational and physical therapists completed the professional form of the ATD PA. Among all participants, 128 devices were prescribed; of these, 86 were still used at 3-mo follow-up. For those abandoned, the most frequent reason given was that the device was no longer needed, although functional improvement (as measured by the FIM) corresponded with device nonuse for just half the devices. Chi-square comparisons of consumer- and therapist-completed forms showed: 1) consumers view some ATs more positively than others, the least positive in this study being walkers; 2) consumers and therapists have different views of the benefits of an AT; and 3) the adaptations required for use of an AT are not well recognized by consumers. The results from the ATD PA indicated that consumers have positive expectations of devices and, if actual performance falls short of expectations, the response may be to discard use of the device; this may be prevented by longer trial periods with devices in a variety of situations (Cushman & Scherer, 1996).

In addition to the studies reported above, a study conducted in Montreal, Quebec, Canada (Vincent & Morin, 1999) showed that items from the Assistive Technology Device Predisposition Assessment (ATD PA) "focus well on the pertinent factors" related to individuals' decisions to use or not use an assistive technology. Another study focused on adolescents who used functional electrical stimulation (FES) to stand and who were administered the ATD PA and several other measures. The results supported the use of the ATD PA and highlighted the need to consider psychosocial aspects of matching person and technology (Brown, 1996; Brown & Merbitz, 1995).

To assess the effectiveness of a college course on adapted computer use, 14 college students with disabilities (more than half having complete or partial) eyesight loss identified factors that influenced them to adopt or reject a device for computer access. The results provide evidence of the usefulness of the MPT model and

ATD PA items as applied to computer access technology for college students (Goodman, Tiene & Luft, 2002). For students in secondary or elementary school, The Educational Technology Predisposition assessment (ET PA), educational researchers have found it to have utility when pre-selecting person characteristics relevant to the use of educational technologies (Albaugh & Fayne, 1996; Albaugh, Piazza & Scholsser,1997).
Other authors have used the MPT model as the theoretical foundation for concept papers or the development of companion assessments (e.g. Beigel, 2000; Demers, Weiss-Lambrau & Ska, 1996, 2002; Zapf & Rough, 2002).
Based on the results of research studies conducted to date, the SOTU, ATD PA and ET PA have been shown to have good reliability and validity and, thus, it can be concluded that they are useful measures both practically and in outcomes research. The testing of the Matching Person & Technology model has determined that the model adequately represents the relevant influences on technology use and non-use or abandonment. Even so, MPT users have said that they require more training in how to maximize benefit from the MPT process and measures and they would like the forms to be scored and interpreted, with a particular focus on next steps and strategies to pursue with consumers. Currently, a beta prototype exists of computerized scoring with interpretations of ATD PA results and a CD interactive program which trains users in the comprehensive MPT process. (Scherer & Cushman, 2002).

Table summarizes the evaluation of the psychometric properties of the MPT assessment.

Table: References for the Psychometric Properties of the MPT Assessments

Reference	MPT form	inter-rater reliability	internal consistency	criterion-related validity	concurrent and construct validity	predictive validity
Scherer & McKee 1992	ATD PA ET PA	√	√	√	√	
Goodman, Tiene & Luft 2002; Scherer & Cushman 2001; Vincent & Morin 1999	ATD PA		√	√	√	√
Scherer & Craddock 2002	ATD PA ET PA SOTU		√	√	√	√
Albaugh & Fayne, 1996; Albaugh, Piazza & Scholsser,1997	ET PA		√	√	√	√
Brown, 1996; Brown & Merbitz, 1995	ATD PA			√	√	
Cushman & Scherer, 1996	ATD PA				√	√
Scherer & Frisina, 1994; Scherer & Frisina, 1998	ATD PA		√	√		

2. Scherer MJ & Craddock G. Matching Person & Technology (MPT) assessment process. Technology & Disability, Special Issue: The Assessment of Assistive Technology Outcomes, Effects and Costs, 2002, 14(3), 125-131

3. Scherer MJ, Cushman LA. Measuring subjective quality of life following spinal cord injury: a validation study of the assistive technology device predisposition assessment. Disabil Rehabil. 2001 Jun 15;23(9):387-93

Purpose: Assesses the validity of a subset of items of the Assistive Technology Device Predisposition Assessment (ATD PA) as a measure of quality of life (QOL) for persons with new spinal cord injury. Method: Subjects completed the ATD PA QOL subset, Satisfaction with Life Scale (SWLS), and Brief Symptom Inventory (BSI) while in acute rehabilitation. The internal reliability of the QOL subset of the ATD PA was assessed. Concurrent validity of the ATD PA's QOL subset with the SWLS and construct validity with the BSI depression subscale was assessed using Spearman correlations. Subjects were recruited while acute rehabilitation inpatients in a general hospital and consisted of twenty persons with newly acquired SCI (10 males and 10 females). Results: Significant positive correlations between the ATD PA's QOL subset and SWLS (and significant negative correlations with the BSI depression subscale) suggest the QOL subset has concurrent and construct validity. Conclusions: The ATD PA's QOL subset appears to be a valid measure and, thus, it can be useful both in identifying subjective quality of life and predispositions to AT use early in rehabilitation.

4. Scherer MJ, Frisina DR. Characteristics associated with marginal hearing loss and subjective well-being among a sample of older adults. J Rehabil Res Dev. 1998 Oct;35(4):420-426

The influence of marginal hearing loss on subjective well-being was studied in order to assess the audiological rehabilitation needs of older individuals. Behavioral and audiological data were obtained from 40 subjects 61-81 years of age. Group A included 20 subjects with normal audiometric thresholds. Group B included 20 subjects with mild-to-moderate degrees of high-frequency hearing loss. Each subject completed a hearing loss screening survey, an Assistive Technology Device Predisposition Assessment (ATD PA) and a Profile of Hearing Aid Performance (PHAP). The PHAP and hearing loss screen were adequate assessments of self-reported hearing loss, as was the subjective rating of hearing section of the ATD PA. People with high-frequency marginal hearing loss reported on the ATD PA less satisfaction with their independence, reduced emotional well-being, and more limitation from their hearing loss than those with normal hearing. It is concluded that marginal degrees of hearing loss in older persons can influence subjective well-being, which suggests the importance of a renewed emphasis on audiological rehabilitation for this population.

MPT SURVEY:
CONSUMER FORM
THE ASSISTIVE TECHNOLOGY DEVICE PREDISPOSITION ASSESSMENT -- C

Name: _____ Date: _____

Desired Outcome(s): _____

_____

A How are your current capabilities in the following areas? Circle the best response for each.

	Excellent		Average		Poor
1. Vision	5	4	3	2	1
2. Hearing	5	4	3	2	1
3. Speech	5	4	3	2	1
4. Upper extremity control	5	4	3	2	1
5. Lower extremity control	5	4	3	2	1
6. Mobility	5	4	3	2	1
7. Dexterity	5	4	3	2	1
8. Learning speed	5	4	3	2	1
9. Physical strength/stamina	5	4	3	2	1

Put a minus sign (-) beside any of the above that you believe are or will be deteriorating over time.

Then put a plus sign (+) beside any you believe are or will be improving over time.

B. How satisfied are you with what you have achieved in the following areas? Please circle the best response for each.

	Very Satisfied		Neutral		Not Satisfied
10. Independent living skills/activities of daily living	5	4	3	2	1
11. Communication skills	5	4	3	2	1
12. Physical comfort and well-being	5	4	3	2	1
13. Overall health	5	4	3	2	1
14. Social and recreational involvement	5	4	3	2	1
15. Ability to go where desired	5	4	3	2	1
16. Educational attainment	5	4	3	2	1
17. Employment status/potential	5	4	3	2	1
18. Emotional well-being	5	4	3	2	1

Put a plus sign (+) beside the one(s) you most want to improve over time.

C. How do you feel about your disability?

	Strongly Agree		Neutral		Strongly Disagree
19. It limits what I want to do	5	4	3	2	1
20. My life would be better without my disability	5	4	3	2	1

D. Please check all the statements below that describe you.

21. I am encouraged by family	32. I am a calm person	43. I find technology interesting
22. I am encouraged by friends	33. I am curious and excited about new things.	44. I am cooperative
23. I am encouraged by therapists	34. I am self-disciplined	45. I prefer a quiet life
24. I have little privacy	35. I want/need to go to school **or** work	46. I often feel isolated and alone
25. I feel the general public accepts me	36. I am patient and easy going	47. I have many things I want to accomplish
26. I am often discouraged	37. I do what my therapist(s) tell me to do	48. I am not sure who I am now
27. I am satisfied with my life	38. I am resourceful	49. I want more independence
28. I like to be alone	39. I like having a challenge	50. I have a good self image
29. I am often angry	40. I have made friends with my therapist(s)	51. I feel insecure
30. I am often depressed	41. I am responsible and reliable	52. I believe my therapist(s) knows what is best for me
31. I accomplish what I set out to do	42. I often feel frustrated	53. I am determined to meet my goals

Name: _____ Date: _____

Device/System): _____

E. How do you feel about using this device?

	This definitely applies to me		This is neutral for me		This does not apply to me
54. I have the assistance and accommodations I need to successfully use this device.	5	4	3	2	1
55. I have the funding to get this device	5	4	3	2	1
56. I will benefit from using this device	5	4	3	2	1
57. This device will help me achieve a goal that I have	5	4	3	2	1
58. This device will improve the quality of my life	5	4	3	2	1
59. With this device, the way I go about doing things will remain the same	5	4	3	2	1
60. I will feel self-conscious using this device around my family	5	4	3	2	1
61. I will feel self-conscious using this device around my friends	5	4	3	2	1
62. I will feel self-conscious using this device at school or work	5	4	3	2	1
63. I will feel self-conscious using this device in public	5	4	3	2	1

SCORING

Disability Items

Sum of items 1-9: ____

Sum of items 10-13: ____

Reverse of item 19: ____

Grand total: ____

Divided by 14 = **Disability** score:____

Environment Items

Sum of items 14-17:

Sum of incentives in Items 21-25:&

Sum of disincentives In items 21-25:

Number of Neutral Items x3:

Sum of 54-55:

Sum of reverse of Items 60-62:

Grand total:

Divided by 14 = **Environment** score:

Temperament Items

Item 18: ____

Sum of reverse of items 19-20: ____

Sum of items 56-58: ____

Sum of reverse of items 60-61: ____

Sum of incentives in items 26-53: ____

Sum of disincentives in items 26-53: ____

Sum of neutral items in 26-53: ____

Grand total: ____

Divided by 36 = **Temperament** score:

Device Items

Sum of items 54-59: ____

Sum of reverse of items 60-63: ____

Grand total: ____

Divided by 10____= **Device score**:____

MPT SURVEY:
PROFESSIONAL FORM
THE ASSISTIVE TECHNOLOGY DEVICE PREDISPOSITION ASSESSMENT (ATD PA)-P

Consumer: _____ Date: _____

Rater: _____

A. Individual and Psychosocial INCENTIVES AND DISINCENTIVES TO ATD USE

Read each of the items below and decide which may be incentives and disincentives/deterrents to the use of assistive technology by this person. Then put an "X" in the appropriate box. For those that are neutral, **do not** apply to or do not exist in this situation, put an "X" in the Neutral/Does Not Apply box.

	Major Disincentive	Moderate Disincentive	Minor Disincentive	Neutral/Does Not Apply	Minor Incentive	Moderate Incentive	Major Incentive
1. Expectations held by family							
2. Expectations held by friends							
3. Interest in new things							
4. Attitude/outlook on life							
5. General life experiences							
6. Degree of social participation							
7. Desire for independence							
8. Desire to work/go to school							
9. View of opportunities							
10. Degree of self-discipline and patience							
11. Degree to which self-image has incorporated the disability							
12. Perceived control over quality of life							

13. Desire to use technology (ies)							
14. Mood and affect							
15. Expectations of self							
16. Self-concept							
17. Social skills							
18. View of limitations/barriers							
19. Degree of expressiveness							
20. Coping skills							
21. Cooperation with therapist and rehabilitation plan							
22. Socialization							
Total Checked (for each column)							

Device/System): Date:

Who wants the device for this person (person, family, therapist, employer)?

B. REQUIREMENTS OF THE ASSISTIVE DEVICE COMPARED TO THE RESOURCES OF THE PERSON

The following items are presented in pairs. The left column asks about the requirements of the device in six different areas; the right column asks about individual resources in each of the same six areas. For every paired item, write in the box the number that best indicates the degree to which the requirements of the device and the resources of the person match. For example, if the person is easily capable of dealing with the device's *physical demands*, or the *physical demands* of the device can easily be modified to accommodate the resources of the person, then a good match exists and the score would be 5 for that particular pair.

5 = A good march exists.

4 = The match is close, but not perfect.

3 = Neutral or does not apply or has not been assessed.

2 = The person will have difficulty.

1 = A clear and obvious mismatch exists.

REQUIREMENTS OF THE ASSISTIVE DEVICE		RESOURCES OF THE PERSON
23. Physical Demands Is the device usable with little or no discomfort, stress and fatigue and is it usable with little or no assistance from others?		Does the person have the physical capabilities and stamina to appropriately use the device?
24. Physical/Sensory Requirements Are there physical requirements for use (e.g. finger dexterity, hearing, sight) that be adapted or modified?		Does the person possess or can the person be trained for the necessary physical/sensory demands?
25. Expenses Is the cost of the device within reason for the expected increased functioning?		Does the person have the resources and/or support to purchase or rent the device?
26. Support Services/Training Is training/support and upgrading available for the device? Can the individual try it out, etc. to make sure a good match exists?		Does the person have the resources and skills to benefit from training and/or support?
27. Service Delivery Can it be delivered in a timely fashion?		Does the person possess the patience to wait for the device and will not outgrow it?
28. Cognitive Demands Does the device require special training/education that is available? Can the device be adapted to accommodate varying user skills/aptitudes?		Does the person have the training and intellectual abilities needed or can s/he be trained to have them?

C. INDIVIDUAL AND PSYCHOSOCIAL CHARACTERISTICS AFFECTING USE OF THE ASSISTIVE DEVICE

	Yes		Possibly		No
29. Does the user have goals that he or she judges will be better or more easily achieved by using the device rather than alternatives to its use?	5	4	3	2	1
30. Will use of the device fit with the person's basic style of doing things?	5	4	3	2	1
31. Does the user have realistic expectations of the device?	5	4	3	2	1
32. Does the user believe that use of the device will result in an enhanced quality of life?	5	4	3	2	1
33 .Does the user want this assistive device?	5	4	3	2	1
34. Will using the device enhance the user's self-esteem?	5	4	3	2	1
35. Will the device give the person positive status in the eyes of peers?	5	4	3	2	1
36. Will the device give the person positive status in the eyes of family members?	5	4	3	2	1
37. Will the device give the person positive status in the eyes of the general public?	5	4	3	2	1
38. Will use of the device be independent of cooperation/assistance from others who may feel inconvenienced by it?	5	4	3	2	1
39. Do the relevant environments fully support use of the device (both architecturally and attitudinally)?	5	4	3	2	1

Sample Items (less than half of the items) of the ATD PA Initial/Baseline *Person* and *Device* Forms (Follow-Up Forms Also Exist)

Name _____ Date of Birth _____

Primary Goals (6 months):_____ Today's Date _____

Primary Goals (1 year+):_____ Form completed by _____

A. How would you rate your abilities today in the following 9 areas using your current AT or other support?

- For items 1-9, circle the best response (1 for *poor* through 5 for *excellent*).
- Under ***Name of Support*** write the name of the support you use where relevant (example: 'eyeglasses' for # 1, *eyesight*).
- Write a plus [+] in the spaces where you expect to need more support over the next year (example: 'eyeglasses' gets [+] if you'll expect to need stronger lenses during the next year). Write a [-] in the spaces where you expect to need less support, and a [0] where you expect your support should stay the same over the next year.

	Poor		Average		Excellent	Name of Support	Need increase [+] or decrease [-]
1. Eyesight	1	2	3	4	5	_____	_____
2. Hearing	1	2	3	4	5	_____	_____
7. Grasping and use of fingers	1	2	3	4	5	_____	_____
9. Mobility	1	2	3	4	5	_____	_____

B. How satisfied are you currently in the following areas?

- For items 10 – 21, circle the best response (1 for *Not Satisfied* through 5 for *Very Satisfied*).
- Under ***Importance*** write #1, #2 or #3 for your three most important areas (#1=most important). Leave the other lines blank.
- Under ***Primary Obstacle*** write an [E] or [PR] to indicate if the primary obstacle you face is due to external, environmental and social barriers [E] or to limitations you experience due to inadequate AT and other personal resources [PR].

	Not Satisfied		Satisfied		Very Satisfied	Importance	Primary Obstacle [E],[PR]
10. Social relationships	1	2	3	4	5	_____	_____
15. Recreational involvement	1	2	3	4	5	_____	_____
16. Freedom to go wherever desired	1	2	3	4	5	_____	_____
17. Educational attainment	1	2	3	4	5	_____	_____
20. Autonomy and independence	1	2	3	4	5	_____	_____
21. Fitting in and belonging	1	2	3	4	5	_____	_____

C. Please circle all the statements below that describe you.

22. I have the support I want from family	33. I am a calm person	44. I find technology interesting
23. I have the support I want from friends	34. I am patient & easy-going	45. I am cooperative
25. I feel the general public accepts me	36. I am often angry	47. I feel isolated & alone
30. I am often frustrated or overwhelmed	41. I like having a challenge	52. I often feel insecure
31. I am curious & excited about new things	42. I am satisfied with my life	53. I feel as if I have little privacy

For Comparing Devices to Meet Desired Outcomes

DIRECTIONS: Read each of the twelve items below (A-L) and circle the letter of the *three* that are most important to you.

A. The assistance and accommodations exist for successful use of this device.
B. This device will physically fit in all desired environments (car, living room, etc.).
D. I will benefit from using this device.
G. This device will improve my quality of life.
H. I have the capabilities and stamina to use this device without discomfort, stress and fatigue.
L. I will feel comfortable (and not self conscious) using this device around the community.

Write the name of each device being considered in the boxes below under ***Device***. Rate each device for the twelve items (A-L) according to the following scale and then write your ratings in the appropriate boxes:

5 = All the time
4 = Often
3 = Half the time, neutral
2 = Sometimes
1 = Not at all
0 = Not applicable

DEVICE	A	B	C	D	E	F	G	H	I	J	K	L	Total (Add A-L)

Review each **total score** above. In general, the device with the highest total score is the one most preferred (maximum number of points=60). However, when total scores are close, more weight should be given to the three items circled as being *most important*.

ATTITUDE SCALE FOR GENERAL PRACTITIONERS & ATTITUDE SCALE FOR DISPENSING CHEMISTS

Attitude Scale for General Practitioners (APMG) and Attitude Scale for Dispensing Chemists (APPO) have been developed by Michèle Baumann. Original instruments have been published in French. The APMG and APPO scales form two, one-dimensional scales. APMG purpose is assess professional attitudes which intervene in the instauration and follow up of patient treatment. APPO purpose is assess professional attitudes which intervene in the instauration and follow up of patient treatment.

Abbreviated Name: APMG-15 (Attitudes Professionnelles des Médecins Généralistes)/ APPO-09 (Attitudes Professionnelles des Pharmaciens d'Officine)
Author(s): Michèle Baumann
Purpose: To assess professional attitudes which intervene in the instauration and follow up of patient treatment
Population: Adult
Type of Instrument: Satisfaction
Mode of Administration:

Rater:	Self-administered
Time required:	10-20 minutes
Response Options:	10-point Likert scale
Scoring:	Global score
Score Direction:	Higher scores show better QoL

Number of Items: APMG: 15 / APPO: 9
Original Language: French

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Contact for information and permission to use:

Michèle Baumann
Université du Luxembourg,
Campus de Walferdange,
BP 2, L-7201 Walferdange
Luxembourg
E-mail : michele.baumann@uni.lu

Key References:

1. Baumann M, Baumann C, Aubry C, Alla F. Échelle des attitudes des médecins généralistes et des pharmaciens d'officine favorisant l'observance thérapeutique [An attitude scale for general practitioners and dispensing chemists who encourage therapeutic compliance] Article in French. Revue Médicale de l'Assurance Maladie 2005; 36(1): 23-33.

Aims: To construct and validate a scale of professional attitudes for both general practitioners (APMG) and dispensing chemists (APPO). Methods: Stage 1. The construction and qualitative validation of a scale. By interviewing 40 patients in a preventive-care center in Lorraine in addition to 21 general practitioners (MG) and 22 dispensing chemists (PO), we targeted items which could possibly help us formalize a theoretical construction of professional attitudes which intervened in the instauration and follow-up of patient treatments. Then, with the help of a group of experts, we determined which generic items in the questionnaire could be validated and, finally, identified the functions which fulfilled these attitudes. Stage 2. We statistically validated the APMG and APPO scales and then studied the metric characteristics of the scales by using a questionnaire which was auto-administered to 393 patients in Lorraine. Results: We isolated 15 relational attitudes associated with information, communication and education in general practitioners and nine in dispensing chemists. The APMG and APPO scales form two, one-dimensional scales. Analysis showed high internal coherence (Cronbach's alpha coefficient was 0.91 and 0.87 respectively) and acceptable reproducibility (the correlation coefficient between classes was respectively 0.74 and 0.72). Conclusion: The competencies we isolated represent important criteria in the quality of interpersonal doctor-patient and chemist-patient relationships. The metric characteristics of the scales (APMG: 15 items and APPO: 9 items) were deemed satisfactory. This suggests that they can be used as an aid in training in the healthcare professional-patient relationship, in decision-making and in assessing relational competencies.

Société Française de Santé Publique

Ecole de Santé Publique
Faculté de Médecine - Nancy

Centre de Médecine Préventive
Evaluation Santé

Attitudes à l'égard du suivi des traitements

☐☐☐ ☐

Date de remplissage: /..../..../ /..../..../ /.../.../.../.../

MERCI DE LIRE AVEC ATTENTION LES CONSIGNES :

Vos réponses à ce questionnaire nous permettront de mieux comprendre :
1 Quelles sont les attitudes de votre médecin, de votre pharmacien et de votre entourage qui vous encouragent à l'observance, c'est-à-dire qui vous aident à suivre la prescription médicale et les conseils préventifs qui vous sont donnés.

COMMENT REMPLIR CE QUESTIONNAIRE :

Pour chacune des phrases du questionnaire:
1 Cochez la case parmi les 10 proposées qui correspond le mieux à votre situation, à ce que vous vivez, entre **"jamais"** et **"toujours"**;

Ce questionnaire est exploité de façon confidentielle.
Les résultats ne seront pas connus des personnes
qui vous prennent en charge dans ce centre.

1 *Il n'y a pas de bonne ou de mauvaise réponse.*
1*C'est ce que vous pensez qui compte.*

Voici un exemple, ne cochez rien:

	Jamais									toujours
Mon médecin m'explique les choses avec des mots simples	θ	θ	θ	X	θ	θ	θ	θ	θ	θ

Ce questionnaire comporte 7 pages au total

Attitudes du médecin
A l'égard du suivi des traitements

Voici une série de phrases sur les attitudes de votre médecin. Merci de cocher pour chacune des phrases suivantes ***la case***, parmi les 10 proposées, qui correspond le mieux à ce que vous vivez, entre jamais et toujours. Il n'y a pas de bonne ou de mauvaise réponse.

	jamais								toujours	
1- mon médecin prend le temps de m'écouter	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ
2- mon médecin fait le nécessaire pour gagner ma confiance	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ
3- mon médecin m'explique à quoi sert le traitement	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ
4- mon médecin tient compte de mes préférences pour la prescription (cachet, gouttes etc.)	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ
5- mon médecin me donne l'impression qu'il me respecte	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ
6- mon médecin m'informe sur les effets secondaires des médicaments	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ
7- mon médecin insiste sur les médicaments importants	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ
8- mon médecin parle avec moi des difficultés que j'ai à suivre le traitement	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ
9- mon médecin m'explique les choses avec des mots simples	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ
10- mon médecin me propose des nouveaux traitements	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ
11- mon médecin écrit lisiblement l'ordonnance	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ
12- mon médecin me laisse poser mes questions	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ
13- mon médecin me motive pour suivre mon traitement	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ
14- mon médecin me donne des conseils de prévention (alimentation, activité sportive…)	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ
15- mon médecin me donne l'impression de connaître son métier	θ	θ	θ	θ	θ	θ	θ	θ	θ	θ

Attitudes du pharmacien à l'égard du suivi des traitements

Voici une série de phrases sur les attitudes du pharmacien. Merci de cocher pour chacune des phrases suivantes ***la case***, parmi les 10 proposées, qui correspond le mieux à ce que vous vivez, entre jamais et toujours. Il n'y a pas de bonne ou de mauvaise réponse.

16- mon pharmacien prend le temps de m'écouter	jamais θ	θ	θ	θ	θ	θ	θ	θ	toujours θ	θ
17- mon pharmacien me propose de changer mon médicament pour un générique	jamais θ	θ	θ	θ	θ	θ	θ	θ	toujours θ	θ
18- mon pharmacien contrôle la prescription de mes médicaments	jamais θ	θ	θ	θ	θ	θ	θ	θ	toujours θ	θ
19- mon pharmacien contacte mon médecin en cas de problème	jamais θ	θ	θ	θ	θ	θ	θ	θ	toujours θ	θ
20- mon pharmacien me donne des conseils de prévention (alimentation, activités, etc.)	jamais θ	θ	θ	θ	θ	θ	θ	θ	toujours θ	θ
21- mon pharmacien a les compétences pour répondre à un problème sur le médicament	jamais θ	θ	θ	θ	θ	θ	θ	θ	toujours θ	θ
22- mon pharmacien écrit sur les boîtes les doses et quand prendre les médicaments	jamais θ	θ	θ	θ	θ	θ	θ	θ	toujours θ	θ
23- mon pharmacien renouvelle les médicaments avant d'avoir l'ordonnance	jamais θ	θ	θ	θ	θ	θ	θ	θ	toujours θ	θ
24- mon pharmacien me motive pour suivre mon traitement	jamais θ	θ	θ	θ	θ	θ	θ	θ	toujours θ	θ

BARTHEL INDEX (MODIFIED)

The original Barthel Index was developed in the USA by Florence Mahoney and Dorothea Barthel (1965). The Modified Barthel Index was developed in Australia by Surya Shah, Frank Vanclay and Betty Cooper (1989). A third version was developed in England by Collin and colleagues (1988).

The original Barthel Index was developed to measure activities of daily living. The 10 subtest items include (1) feeding, (2) moving from wheelchair to bed and return, (3) personal grooming, (4) getting on/off the toilet, (5) bathing, (6) walking or propelling a wheelchair , (7) stair climbing, (8) dressing and undressing, (9) bowel and (10) bladder continence.. Each subtest item on the original Barthel Index is rated 0, 5 or 10 (or 15 for two of the test items). Maximum total score is 100.

The Modified Barthel Index includes the same 10 subtest items, scored on a 5-point ordinal scale which varies from item to item (eg 0, 1, 3, 4, or 5 for personal hygiene; 0, 3, 8, 12 or 15 for ambulation). This scale was developed to enhance the sensitivity of the original scale. The Modified Barthel Index scores the degree of independence of a client from any assistance (regardless of how minor, and for what purpose the assistance is provided). Maximum total score is 100.

The 20-point Barthel Index includes the same 10 subtest items with variable sub-scores between 0 and 3. For example, bathing can be rated 0 (dependent) or 1 (independent), while transferring can be rated 0 (unable, no sitting balance), 1 (major help one or two people, physical contact), 2 (major help, verbal or physical), or 3 (independent). Maximum total score is 20.

The original Barthel Index uses weighted scoring, with subtest scores ranging from 0 to 15 with increments of 5. A total score of 100 represents the highest level of independence although a perfect score does not necessarily mean that a person is able to perform instrumental activities of daily living. The total score is not as meaningful as the breakdown into individual subtest scores, since these indicate where limitations exist. The Modified Barthel Index and 20-point Barthel Index also use weighted scoring.

Abbreviated Name: BI
Author(s): Surya Shah, Frank Vanclay, Betty Cooper
Purpose: To assess all chronic disabilities + acute stages
Population: Adult
Age Range : 16-99 years
Type of Instrument: Disability / Physical functioning
Mode of Administration:

Rater:	Self-/ Proxy-administered
Time required:	12 minutes for self-report status, 10 minutes for a telephone interview to 40 minutes for direct observation of all tasks
Response Options:	Each item is rated in terms of whether the patient can perform the task indenpendently; with some assisstance, or is dependent.
Scoring:	Global score
Score Direction:	Higher scores show better QoL

Number of Items: 10
Original Language: English
Existing Translations : Chinese, German, Greek, Hindi, Italian, Japanese, Polish

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Contact for information and permission to use:

Dr. Surya SHAH
College of Allied Health Sciences
The University of Tennessee
822 BEALE, Suite 345
Memphis, TN 38163 USA
Fax: +1- 901-763-0150
Email: Sushah@utmem.edu
Email: shahsurya@hotmail.com

Dimensions covered by the questionnaire :

- Physical function self care (10 items, unidimensional scale)

Key References:

1. Shah S, Vanclay F, Cooper B (1989) Improving the sensitivity of the Barthel Index for stroke rehabilitation. Journal of Clinical Epidemiology, 42, 703-709.

The Barthel Index is considered to be the best of the ADL measurement scales. However, there are some scales that are more sensitive to small changes in functional independence than the Barthel Index. The sensitivity of the Barthel Index can be improved by expanding the number of categories used to record improvement in each ADL function. Suggested changes to the scoring of the Barthel Index, and guidelines for determining the level of independence are presented. These modifications and guidelines were applied in the assessment of 258 first stroke patients referred for inpatient comprehensive rehabilitation in Brisbane, Australia during 1984 calendar year. The modified scoring of the Barthel Index achieved greater sensitivity and improved reliability than the original version, without causing additional difficulty or affecting the implementation time. The internal consistency reliability coefficient for the modified scoring of the Barthel Index was 0.90, compared to 0.87 for the original scoring.

Modified Barthel Index

(Notes in parenthesis are to facilitate application)

Personal Hygiene

1. The patient is unable to attend to personal hygiene and is dependent in all aspects.

> [Patient is totally dependent on assistance to brush teeth/denture, comb hair, wash hands, wash face, shave and/or apply make-up.]

2. Assistance is required in all steps of personal hygiene.

> [Patient may complete one or two of the above activities. Generally requires assistant to provide more effort than self for each of the activities, loosen dentures, shave etc.]

3. Some assistance is required in one or more steps of personal hygiene.

> [Assistance is required in applying make-up, help to wash one hand, help to apply pressure to brush teeth, shave under chin, comb back of hair, help to dry one hand. Needs constant cueing or coaxing to complete tasks.]

4. Patient is able to conduct his/her own personal hygiene but requires minimal assistance before and/or after the operation.

> [There may be concerns about safety such as plugging in plug, fixing a razor blade, hot water or some assistance may be required with set up and/or tidy up or smoothing smudged make-up.]

5. The patient can wash his/her hands and face, comb hair, clean teeth and shave. A male patient may use any kind of razor but must insert the blade, or plug in the razor without help, as well as retrieve it from the drawer or cabinet. A female patient must apply own make-up, if used, but need not braid or style her hair.

> [Patient can perform all personal hygiene tasks independently and safely.]

Bathing Self

1. Total dependence in bathing self.

> [Patient is totally dependent in bathing self, or bathing is not performed or drying all parts of the body is not performed.]

2. Assistance is required in all aspects of bathing.

> [Patient requires assistance and direction in all aspects of bathing. May be able to wash chest and both arms.]

3. Assistance is required with either transfer to shower/bath or with washing and drying; including inability to complete a task because of condition or disease, etc.

> [Assistance is required with either transfer to shower/bath or washing/drying. Help with bathmit, soap, towel, wash cloth, upper and/or lower limbs may be required. Patient may need cueing, coaxing and supervision.]

4. Supervision is required for safety in adjusting the water temperature, or in the transfer.

> [Bathing may take more than three times the normal time. Assistance may be required to set up bathing equipment, the water, washing material, etc. Some prompting or supervision with transfers may be required.]

5. The patient may use a bath tub, shower, or take a complete sponge bath. The patient must be able to do all the steps of whichever method is employed without another person being present.

> [Patient may use specialised equipment, long-handled sponge to wash legs and feet. Patient is able to complete all steps independently, and may take up to twice the normal time to complete the tasks.]

Feeding

1. Dependent in all aspects and needs to feed.

> [Patient only chews and swallows food while an assistant scoops and brings it to mouth. Maximum help with tube feeding such as pouring, connecting, purging, regulating the rate is required.]

2. Can manipulate an eating device, usually a spoon, but someone must provide active assistance during the meal.

> [Patient can bring food to mouth but an assistant scoops all food onto the utensil.]

3. Able to feed self with supervision. Assistance is required with associated tasks such as putting milk and sugar into tea, adding salt and pepper, spreading butter, turning a plate or other "set up" activities.

> [Patient scoops food, brings it to mouth, and eats. May need assistance with pouring, drinking, opening containers and/or cutting meat, with application of cuff, orthosis, prosthesis. Assistance with set up is required. Standing by cueing, coaxing and supervision throughout meal may be required for possible choking and eating in a hurry.]

4. Independence in feeding with prepared tray except assistance may be required to cut meat, open milk carton, jar lid etc. Presence of another person is not required.

> [Longer than usual time is taken to eat. There may be some concern for safety due to quality of swallowing or may require modified food for consistency, but no further help from assistant is required.]

5. The patient can feed self from tray or table when someone puts the food within reach. The client must put on an assistive device if needed, cut the food, and, if desired, use salt and pepper, spread butter etc.

[The patient is able to use spoon, fork, cup, glass, long straw, adapted devices, cuff, opens containers, pours liquid, and cuts meat with no risk. No help required.]

Toilet

1. Fully dependent in toileting.

[Patient is dependent in all aspects of toileting.]

2. Assistance required in all aspects of toileting.

[Patient requires maximal assistance with transfers, clothing adjustment, use of toilet paper and perineal hygiene.]

3. Assistance may be required with management of clothing, transferring, or washing hands.

[Supervision and assistance with transfer/balance while washing hands, adjusting clothing, with zipping/unzipping fly/skirt, may be required.]

4. Supervision may be required for safety with normal toilet. A commode may be used at night but assistance is required for emptying and cleaning.

[Supervision for safety, initial preparation such as handing the patient the toilet tissue may be required. May use commode at night. Prompting and cueing to locate toilet may be required.]

5. The patient is able to get on and off the toilet, fasten and unfasten clothes, prevent soiling of clothes and use of toilet paper without help. If necessary, the client may use a bedpan or commode, or urinal at night, but must be able to empty it and clean it.

[Patient adjusts clothing prior to using the toilet, wipes front or back, approaches, gets on and off the toilet, adjusts clothing after using the toilet, and fastens clothing. Can use required equipment such as tongs, dressing stick, zipper-pull, or grab bars. Maintains balance and is safe.]

Stair Climbing

1. The patient is unable to climb stairs.

[The stairs imply a flight of stairs.]

2. Assistance is required in all aspects of stair climbing, including assistance with walking aids.

3. The patient is able to ascend/descend but is unable to carry walking aids, and needs supervision and assistance.

4. Generally, no assistance is required. At times, supervision is required for safety due to morning stiffness, shortness of breath, etc.

5. The patient is able to go up and down a flight of stairs safely without help or supervision. The patient is able to use hand rails, cane or crutches when needed and is able to carry these devices as he/she ascends or descends.

Dressing

1. The patient is dependent in all aspects of dressing and is unable to participate in the activity.

> [Patient may lean forwards, backwards, may be able to use bed side rails, may thread a sleeve or bring a garment together, but the assistant dresses client totally. If patient wears a gown, the score is 0.]

2. The patient is able to participate to some degree, but is dependent in all aspects of dressing.

> [Patient requires maximal assistance in set up dressing. Patient may wear a sweat shirt on his upper body and thread the sleeves, but assistant brings it over the head. Patient can thread bra straps but the assistant fits and fastenss the bra hook. Patient may assist pulling the pant legs but the assistant completes the lower limb dressing.]

3. Assistance is needed in putting on and/or removing any clothing.

> [Assistance is needed in obtaining clothing, applying devices, and initiating and completing upper and lower extremity dressing and undressing.]

4. Only minimal assistance is required with fastening clothing, such as buttons, zips, bra, shoes, etc.

> [Patient may require start up assistance but patient dresses and undresses. Assistant may obtain clothing from closet, may assist in application of orthosis or prosthesis, and may assist with fastening clothing, buttons, zips, bra etc. Coaxing, prompting and/or cueing on sequencing may be required and dressing may take up to three times the normal time.]

5. The patient is able to put on, remove and fasten clothing, tie shoe laces, or put on, fasten and remove corset or brace as prescribed.

> [Patient is able to obtain clothes, put on, remove and fasten clothing and shoe laces, or put on, fasten and remove corset, brace or prosthesis as prescribed. Patient manages underpants slacks, skirt, belt, stockings and shoe laces. Patient manages bra, turtle necks, zippers, buttons and snaps, and can use special adaptive closure such as velcro and zipper pull, and dressing stick, reacher, sock aid, and completes task in reasonable time.]

Bowel Control

1. The patient is bowel incontinent.

[The patient needs to wear dipers, or absorbent pads.]

2. The patient needs help to assume appropriate position, and with bowel movement facilitatory techniques.

[Despite assistance, patient may be soiled frequently and necessitates wearing absorbent pads.]

3. The patient can assume appropriate position, but cannot use facilitatory techniques, or clean self without assistance, and has frequent accidents. Assistance is required with incontinence aids, such as pads etc.

[Patient can assume position, but has occasional accidents, needs assistance to clean self and/or to apply incontinence aids.]

4. The patient may require supervision with the use of suppository or enema, and has occasional accidents.

[Patient requires supervision with the use of suppository, enema, or an external device. Bowel accidents are rare, and prompting, cueing and adherence to the routine to maintain continence may be required.]

5. The patient can control bowels completely and has no accidents. Can use suppository, or take an enema when necessary.

[Patient can control bowels completely and intentionally and has no accidents, can use digital stimulation or stool softeners, suppositories, laxative use, or enemas on a regular basis. If patient has colostomy he/she maintains it.]

Bladder Control

1. The patient is dependent in bladder management, is incontinent, or has indwelling catheter.

[Patient may be catheterised, is incontinent of urine day and night, wet on daily basis. External catheter, drainage bag, night bag, all require to be cared for by assistant.]

2. The patient is incontinent but is able to assist with the application of an internal or external device.

[Patient requires to be positioned but can hold bedpan or urinal in place. External urinary drainage devices, tubing drainage bag, all require to be cared for. Patient is incontinent but able to assist with application of devices.]

3. The patient is generally dry by day, but not at night, and needs assistance with devices.

> [Patient voids but needs help in positioning self, equipment, pads, and other devices. Can place penis in the urinal, hold legs apart, insert catheter, and is occasional incontinent. Coaxing, cueing and supervision may be required.]

4. The patient is generally dry by day and night but may have an occasional accident, or need minimal assistance with internal or external devices.

> [If unable to find toilet or of not quick enough, patient may have an accident. May require minimal assistance with set-up and/or devices, may need medication to maintain voiding pattern. Prompting, cueing and adherence to the routine to maintain continence may be required.]

5. The patient is able to control bladder day and night and/or is independent with internal or external devices.

> [Patient is independent, is continent, and independent in the use of equipment required and use of medication. Is able to change pads, diapers, before soiling.]

Ambulation

1. Dependent in ambulation.

> [Patient does not ambulate. To attempt to ambulate requires two assistants.]

2. Constant presence of one or more assistants is required during ambulation.

> [Patient requires maximal assistance to ambulate.]

3. Assistance is required with reaching aids and/or their manipulation. One person is required to offer assistance.

> [Patient requires assistant to reach for walking aids and to provide a steadying effect around corners, over thresholds, and over rougher terrains, but is able to ambulate.]

4. The patient is independent in ambulation but unable to walk 50m without help. or supervision is needed for confidence or safety in hazardous situations.

> [Patient may require cueing and prompting, and more than reasonable time to complete distances.]

5. The patient must be able to wear braces if required, lock and unlock these braces, assume standing position, sit down and place the necessary aids in position for use. The patient must be able to use crutches, canes, or walkerette and walk 50m/yds without help or supervision.

> [Patient walks length of corridor back and forth. There is no concern for safety, falling or wandering. Patient is independent with walker, cane, prosthesis, orthosis, special shoe etc.]

Do not score ambulation if patient is unable to ambulate and is trained in wheelchair management.

Or Wheelchair

1. Dependent in wheelchair ambulation.

2. The patient can propel self short distances on flat surface but assistance is required for all other steps of wheelchair management.

> [Assistant needs to push wheelchair for the majority of the time, is especially required to apply brakes, adjust armrests, cushion, manoeuver around furniture, over ledges, loose rugs, and rougher terrains.]

3. Presence of one person is necessary and constant assistance is required to manipulate chair to table, bed, etc.

> [Patient can propel wheelchair, but needs assistance with manoeuvering in and around furniture and in limited spaces.]

4. The patient can propel self for a reasonable duration over regularly encountered terrain. Minimal assistance may be required in tight corners.

> [Occasional verbal prompting and assistance with manoeuvering in limited spaces may be required.]

5. To propel wheelchair independently the patient must be able to go around corners, turn around, manoeuver the chair to a table, bed, toilet, etc. The patient must be able to push the chair at least 50 m/yards.

Not applicable if patient is able to ambulate.

Chair/bed transfers

1. Unable to participate in transfer. Two attendants are required to transfer the patient with or without a mechanical device.

2. Able to participate, but maximum assistance of one other person is required in all aspects of the transfer.

3. The transfer requires assistance of one other person. Assistance may be required in any aspect of the transfer.

4. The presence of another person is required, either as a confidence measure, or to provide supervision for safety.

> [Can position sliding board or move footrest or set-up, position chair, and lock brakes. Minimal help is required.]

5. The patient can safely approach the bed in a wheelchair, lock the brakes, lift the footrests, move safely to bed, lie down, come to a sitting position on the side of the bed, change the position of the wheelchair, transfer back into it safely. The patient must be independent in all phases of the activity.

> [Patient can come to a standing position if walking is the mode of locomotion. If walking, client approaches, sits down, and gets t a standing position from a regular chair, transfers from bed to chair, performs tasks safely. Can approach, enter, and leave a tub or shower stall. Patient may use a sliding board, a lift, grab bars, or special seat. Patient may take more than the usual time, but less than three times the usual time to perform tasks.]

The following Table sets out the way in which the Modified Barthel Index is scored

Item	Unable to perform task	Substantial help required	Moderate help required	Minimal help required	Fully dependent
Personal hygiene	0	1	3	4	5
Bathing self	0	1	3	4	5
Feeding	0	2	5	8	10
Toilet	0	2	5	8	10
Stair climbing	0	2	5	8	10
Dressing	0	2	5	8	10
Bowel control	0	2	5	8	10
Bladder control	0	2	5	8	10
Ambulation	0	3	8	12	15
or Wheelchair*	0	1	3	4	5
Chair/Bed transfer	0	3	8	12	15

*Score only if patient is unable to ambulate and is trained in wheelchair management

The following Table sets out the dependency needs

Categories	MBI Total Scores	Dependency Level	Hours of Help Required per Week (maximum)
1	0 – 24	Total	27.0
2	25 – 49	Severe	23.5
3	50 – 74	Moderate	20.0
4	75 – 90	Mild	13.0
5	91 – 99	Minimal	<10.0

Example

A.D.L. INDEX PATIENT'S NAME : FILE NO :						
ITEMS	ADMISSION DATE	IN-CARE DATE	IN-CARE DATE	IN-CARE DATE	DISCHARGE DATE	FOLLOW-UP DATE
Personal Hygiene						
Bathing Self						
Feeding						
Toilet						
Stair Climbing						
Dressing						
Bowel Control						
Bladder Control						
Ambulation						
Wheelchair						
Chair/Bed Transfers						

RANGE						

Date: Score Sheet No:		Score	OT Summary
1. Personal Hygiene			
2. Bathing			
3. Feeding			
4. Toileting			
5. Dressing			
6. Transfers			
7. Ambulation/wheelchair			
8. Stairs			
9. Bladder			
10. Bowel			
Total		100	Signed:
Time taken for self care			Occupational Therapist

Modified Barthel Index – Self Administration
PLEASE CIRCLE ONLY THOSE THAT YOU CAN ACTUALLY DO

Personal Hygiene
1. I am unable to wash my hands, face, comb hair, clean teeth, or shave.
2. I try but I need a lot of help in all steps of above activities.
3. I need only some help in one or more of the activities.
4. I am able to do these activities on my own but need someone to watch me or need minimal help before or after the activity.
5. I can wash hands and face, comb hair, clean teeth, and shave.

Bathing Self
1. I am unable to bathe.
2. I try but I need a lot of help in completing bathing.
3. I need help with either transfer to shower or bath or with washing or drying. I am unable to complete bathing because of my illness.
4. I need supervision because I feel unsafe in adjusting the water temperature, or need help with the transfer.
5. I can use a bathtub or a shower, or take a complete sponge bath. I am able to do all the steps without another person being present.

Feeding
1. I am dependent in feeding and need to be fed.
2. I can use a spoon or knife and fork, but someone must help me with eating.
3. I am able to feed but need to be supervised or I need help with putting milk and sugar into tea, adding salt and pepper, spreading butter, turning a plate or other “set up”.
4. I am independent in feeding when tray is made ready with cut meat, open milk carton or open jar lid. Once the tray is ready, I don’t need anyone to be present when I am eating.
5. I am able to feed from a tray or table when someone puts the food within my reach. I can eat my meals on my own.

Toilet
1. I am unable to go to toilet and need all help I can get.
2. I try but need help with clothing, transferring, or washing hands.
3. I am unsafe with normal toilet and need to be checked if I have wiped clean or need supervision with fastening.
4. I use commode at night but need help with emptying and cleaning.
5. I am able to get on and off the toilet, fasten and unfasten clothes. I don’t soil clothes and use toilet paper without help. If I have to use a bedpan or commode, or urinal at night, I can empty it and clean it.

Stair Climbing

1. I am unable to climb a flight of stairs.
2. I try but I need help in all aspects of stair climbing, including assistance with walking aids.
3. I can go up and down the stairs but I am unable to carry crutches or walking stick, and needs supervision and help at times.
4. I need no help but at times need supervision for safety due to morning stiffness, shortness of breath, etc.
5. I am able to go up and down a flight of stairs safely without help or supervision. I can use handrails, cane, or crutches when needed and am able to carry these devices as I go up or down.

Dressing

1. I am unable to dress.
2. I try to dress, but I am dependent in most of my dressing.
3. I need help in putting on and/or removing my clothing.
4. I need only minimal help with fastening clothes, such as buttons, zips, bra, shoes, etc.
5. I am able to put on, remove and fasten clothing, tie shoelaces, or put on, fasten and remove corset or braces.

Bowel Control

1. I am incontinent.
2. I try but need help to assume appropriate position, and with suppository or other bowel movement techniques.
3. I can take appropriate position, but cannot insert or use other methods, or clean self without assistance, and have frequent accidents. I also need help with incontinence aids, such as pads, etc.
4. I may require supervision with the use of suppository or enema, and have occasional accidents.
5. I can control bowels and have no accidents. I can use suppository, or take an enema when necessary.

Bladder Control

1. I am dependent in bladder management, am incontinent, or I have a catheter.
2. I am incontinent but am able to assist with the application of an internal or external device.
3. I am dry by day, but not at night, and need some help with the devices.
4. I am dry by day and night but may have an occasional accident, or need minimal help with internal or external devices.
5. I am able to control bladder day and night and I am independent with internal or external devices.

Chair/bed transfers

1. I am unable to transfer. Two people are required to move me with or without a lift.
2. I can help but need maximum help of one other person in all aspects of the transfer.
3. I need help of one other person. Sometimes, I may need help with the transfer.
4. I need another person to be present as I am not fully confident or to make sure I am safe
5. I can safely approach the bed in a wheelchair, lock the brakes, lift the footrests, move safely to bed, lie down, come to a sitting position on the side of the bed, change the position of the wheelchair, transfer back into it safely. I am independent in all phases of the activity.

Please do not score walking if you are unable to walk and use wheelchair.

Walking

1. I can't walk.
2. I try to stand up but need one or more persons to help during walking.
3. I need help with reaching aids or need help in using them. One person is required at all times.
4. I am independent in walking but am unable to walk 50 meters without help or supervision is needed for confidence or safety in hazardous situations.
5. I can wear braces if required, lock and unlock these braces, assume standing position, sit down and place the necessary aids in position for use. I am also able to use crutches, canes, or a walker and walk 50 m/yards without help or supervision.

Please do not score if you are able to walk.

Wheelchair

1. I am wheelchair dependent.
2. I can push chair for short distances on flat surface but help is required for all other steps of wheelchair management.
3. I need one person and constant help to manipulate chair to table, bed, etc.
4. I can push chair for a reasonable duration on smooth surfaces but need help when outdoors. I sometimes need help in tight corners.
5. I can use wheelchair independently and can go around corners, turn around, maneuver the chair to a table, bed, toilet, etc. I can push the chair at least 50 m/yards

Modified Barthel Index – Short Protocol (ONCE EXPERIENCED)

Personal Hygiene
- **0** The patient is unable to attend to personal hygiene and is dependent in all aspects.
- **1** Assistance is required in all steps of personal hygiene.
- **3** Some assistance is required in one or more steps of personal hygiene.
- **4** Patient is able to conduct his/her own personal hygiene but requires minimal assistance before and/or after the operation.
- **5** The patient can wash his/her hands and face, comb hair, clean teeth and shave.

Bathing Self
- **0** Total dependence in bathing self.
- **1** Assistance is required in all aspects of bathing.
- **3** Assistance is required with either transfer to shower/bath or with washing or drying; including inability to complete as task because of condition or disease, etc.
- **4** Supervision is required for safety in adjusting the water temperature, or in the transfer.
- **5** The patient may use a bathtub, a shower, or take a complete sponge bath. The patient must be able to do all the steps of whichever method is employed without another person being present.

Feeding
- **0** Dependent in all aspects and needs to be fed.
- **2** Can manipulate an eating device, usually a spoon, but someone must provide active assistance during the meal.
- **5** Able to feed self with supervision. Assistance is required with associated tasks such as putting milk and sugar into tea, adding salt and pepper, spreading butter, turning a plate or other "set up" activities.
- **8** Independence in feeding with prepared tray except assistance may be required to cut meat, open milk carton, jars lid, etc. Presence of another person is not required.
- **10** The patient can feed self from a tray or table when someone puts the food within reach. The client must put on an assistive device if needed, cut the food, and if desired, use salt and pepper, spread butter, etc.

Toilet
- **0** Fully dependent in toileting. [Patient is dependent in all aspects of toileting.]
- **2** Assistance required in all aspects of toileting.
- **5** Assistance may be required with management of clothing, transferring, or washing hands.
- **8** Supervision may be required for safety with normal toilet. A commode may be used at night but assistance is required for emptying and cleaning.
- **10** The patient is able to get on and off the toilet, fasten and unfasten clothes, prevent soiling of clothes and use toilet paper without help. If necessary, the client may use a bedpan or commode, or urinal at night, but must be able to empty it and clean it.

Stair Climbing
- **0** The patient is unable to climb stairs. [The stairs imply a flight of stairs.]
- **2** Assistance is required in all aspects of stair climbing, including assistance with walking aids.
- **5** The patient is able to ascend/descend but is unable to carry walking aids, and needs supervision and assistance.
- **8** Generally, no assistance is required. At times, supervision is required for safety due to morning stiffness, shortness of breath, etc.
- **10** The patient is able to go up and down a flight of stairs safely without help or supervision. The patient is able to use handrails, cane, or crutches when needed and is able to carry these devices as he/she ascends or descends.

Dressing
- **0** The patient is dependent in all aspects of dressing and is unable to participate in the activity.
- **2** The patient is able to participate to some degree, but is dependent in all aspects of dressing.
- **5** Assistance is needed in putting on and/or removing any clothing.
- **8** Only minimal assistance is required with fastening clothing, such as buttons, zips, bra, shoes, etc.

- **10** The patient is able to put on, remove and fasten clothing, tie shoelaces, or put on, fasten and remove corset or braces as prescribed.

Bowel Control
- **0** The patient is bowel incontinent.
- **2** The patient needs help to assume appropriate position, and with bowel movement facilitatory techniques.
- **5** The patient can assume appropriate position, but cannot use facilitatory techniques, or clean self without assistance, and has frequent accidents. Assistance is required with incontinence aids, such as pads, etc.
- **8** The patient may require supervision with the use of suppository or enema, and has occasional accidents.
- **10** The patient can control bowels and has no accidents. Can use suppository, or take an enema when necessary.

Bladder Control
- **0** The patient is dependent in bladder management, is incontinent, or has indwelling catheter.
- **2** The patient is incontinent but is able to assist with the application of an internal or external device.
- **5** The patient is generally dry by day, but not at night, and needs some assistance with the devices.
- **8** The patient is generally dry by day and night but may have an occasional accident, or need minimal assistance with internal or external devices.
- **10** The patient is able to control bladder day and night and/or is independent with internal or external devices.

Ambulation
- **0** Dependent in ambulation.
- **3** Constant presence of one or more assistants is required during ambulation.
- **8** Assistance is required with reaching aids and/or their manipulation. One person is required to offer assistance.
- **12** The patient is independent in ambulation but unable to walk 50 m without help or supervision is needed for confidence or safety in hazardous situations.
- **15** The patient must be able to wear braces if required, lock and unlock these braces, assume standing position, sit down and place the necessary aids in position for use. The patient must be able to use crutches, canes, or a walkerette and walk 50 m/yards without help or supervision.

Do not score ambulation if patient is unable to ambulate and is trained in wheelchair management.

Or Wheelchair
- **0** Dependent in wheelchair ambulation.
- **1** The patient can propel self short distances on flat surface but assistance is required for all other steps of wheelchair management.
- **3** Presence of one person is necessary and constant assistance is required to manipulate chair to table, bed, etc.
- **4** The patient can propel self for a reasonable duration over regularly encountered terrain. Minimal assistance may be required in tight corners.
- **5** To propel wheelchair independently the patient must be able to go around corners, turn around, maneuver the chair to a table, bed, toilet, etc. The patient must be able to push the chair at least 50 m/yards.

Not applicable if patient is able to ambulate.

Chair/bed transfers
- **0** Unable to participate in transfer. Two attendants are required to transfer the patient with or without a mechanical device.
- **3** Able to participate, but maximum assistance of one other person is required in all aspects of the transfer.
- **8** The transfer requires assistance of one other person. Assistance may be required in any aspect of the transfer.
- **12** The presence of another person is required, either as a confidence measure, or to provide supervision for safety.
- **15** The patient can safely approach the bed in a wheelchair, lock the brakes, lift the footrests, move safely to bed, lie down, come to a sitting position on the side of the bed, change the position of the wheelchair, transfer back into it safely. The patient must be independent in all phases of the activity.

Barthel index

"The Barthel Index (formerly: The Maryland Disability Index) is a rating scale completed by a nurse, physiotherapist or doctor from medical records or from direct observation. The ten activities assessed are shown below, together with the corresponding scores. Mahoney and Barthel provided extensive definitions of the levels of independence included in the index (not exhibited here). A score of 0, 5, 10 or 15 is assigned to each level; overall scores range from 0 to 100. The scores are intended to reflect the amount of time and assistance a patient requires."

		With help	Independent
1.	Feeding (if food needs to be cut up = help)	5	10
2.	Moving from wheelchair to bed and return (includes sitting up in bed)	5-10	15
3.	Personal toilet (wash face, comb hair, shave, clean teeth)	0	5
4.	Getting on and of toilet (handing clothes, wipe, flush)	5	10
5.	Bathing self	0	5
6.	Walking on level surface (or if unable to walk, propel wheelchair)	10	15
7.	Ascend and descend stairs	5	10
8.	Dressing (includes tying shoes, fastening fasteners)	5	10
9.	Controlling bowels	5	10
10.	Controlling bladder	5	10

Reproduced from Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index. Maryland Stat Med J 1965; 14:62.
Note: a score of zero is given where patients cannot meet the defined criterion.

The 20-point Modified Barthel Index (Collins Scoring)

Item	Score	Item	Scoring instructions	Score
1: Bowels	0 1 2	Incontinent (or needs to be given enema) Occasional accident (once/week) Continent	Rate based on the last week. If needs enema from nurse, then incontinent. Occasional = once a week.	
2: Bladder	0 1 2	Incontinent, or catheterised and unable to manage Occasional accident (max. once per 24 hours) Continent (for over 7 days)	Rate based on the last week. Occasional = less than once a day. A person with a catheter who can completely manage the catheter alone is scored 'continent'.	
3: Grooming	0 1	Needs help with personal care Independent face/hair/teeth/shaving	Rate based on the last week. Refers to personal hygiene: doing teeth, fitting false teeth, doing hair, shaving, washing face. Implements can be provided by helper.	
4: Toilet use	0 1 2	Dependent Needs some help, but can do something alone. Independent (on and off, dressing, wiping). Should be able to reach toilet/commode, undress sufficiently, clean self, dress and leave.	With help = can wipe self and do some of the other listed activities.	
5: Feeding	0 1 2	Unable Needs help cutting, spreading butter etc. Independent (food provided in reach). Able to eat any normal food (not only soft food). Food cooked and served by others. But not cut up.	Help = food cut up, consumer feeds self.	
6: Transfer (from bed to chair and back)	0 1 2 3	Unable - no sitting balance Major help (one or two people, physical), can sit. Minor help (verbal or physical) Independent	Dependent = no sitting balance (unable to sit); two people to lift. Major help = one strong/skilled, or two normal people. Can sit up. Minor help = one person easily, OR needs any supervision for safety.	
7: Mobility	0 1 2 3	Immobile Wheelchair independent including corners etc. Walks with help of one person (verbal or physical) Independent (but may use any aid, eg. stick)	Refers to mobility about the house or ward, indoors. May use aid. If in wheelchair, must negotiate corners/doors unaided. Help = by one, untrained person, including supervision/moral support.	
8: Dressing	0 1 2	Dependent Needs help, but can do about half unaided Independent (including buttons, zips, laces, etc.)	Should be able to select and put on all clothes, which may be adapted. Half = help with buttons, zips, etc. (check!), but can put on some garments alone.	
9: Stairs	0 1 2	Unable Needs help (verbal, physical, carrying aid) Independent up and down	May carry any walking aid to be independent.	
10: Bathing (or showering)	0 1	Dependent Independent (or in shower)	Usually the most difficult activity. Must get in and out unsupervised, and wash self. Independent in shower = independent if unsupervised/unaided	
Total score (out of 20)				

BODY IMAGE QUESTIONNAIRE

Body Image Questionnaire has been developed by Ulrich Clement, &Bernd Löwe. Original instruments has been published in German. This instrument purpose is assess body image disturbances. The BIQ consists of 20 items assessing the dynamic body image and rejected body image.

Abbreviated Name: FKB20 (Fragebogen zum Körperbild)
Author(s): Ulrich Clement, Bernd Löwe
Purpose: To assess body image disturbances
Population: Adult
Age Range: years
Type of Instrument: Quality of Life / Psychosocial/ Psychological / Satisfaction
Mode of Administration:

Rater:	Self-administered
Time required:	10 - 20 minutes
Response Options:	5-point Likert scale
Scoring:	Global score Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 20
Original Language: German
Existing Translations: English, Dutch, French, Polish

Contact for information and permission to use:

Prof Dr. Ulrich Clement
Psychosomatische Klinik der
Universitat Heidelberg
Thibaustr. 2
69115 Heidelberg, Germany

Kußmaulstr. 10
D-69120 Heidelberg, Germany
Tel.: 06221-406432
Fax: 06221-406422
E-Mail: info@ulclement.de

Dimensions covered by the questionnaire :

- Rejected body image
- Dynamic body image

Key References:

1. Clement U, Lowe B.[Validation of the FKB-20 as scale for the detection of body image distortions in psychosomatic patients] Psychother Psychosom Med Psychol.. 1996 Jul;46(7):254-9.

The study examines the validity of a body image questionnaire (FKB-20) assessing body image disturbances in a clinical sample (n = 405 outpatients of a psychosomatic clinic) and two non-clinical samples (n = 141 medical students and n = 208 sports students). The criterion group was constituted by 98 patients of the clinical sample with diagnosed body image disturbances (anorexia, transsexualism, hypochondriac symptoms). The validity coefficients were 0.56-0.65. The sensitivity of the questionnaire was 82-90%, the specificity 90-97%, and the total mistake rate was 8-10%. The FKB-20 proves to have good validity and can be used for the diagnosis of body image disturbances.

Fragebogen zum Körperbild (FKB-20)

Dieser Fragebogen beschreibt das körperliche Empfinden und die Einstellung zum eigenen Körper.
Bitte kreuzen Sie bei den folgenden 20 Aussagen an, inwieweit die Aussagen für Sie selbst gegenwärtig zutreffen.

		trifft nicht zu	trifft kaum zu	trifft teil-weise zu	trifft weit-gehend zu	trifft völlig zu
1.	Insgesamt empfinde ich mich als robust und stark.	❑	❑	❑	❑	❑
2.	Mit meinem Aussehen stimmt etwas nicht so recht.	❑	❑	❑	❑	❑
3.	Ich bin gesund.	❑	❑	❑	❑	❑
4.	Manchmal spüre ich eine unbändige Energie in mir.	❑	❑	❑	❑	❑
5.	Ich kann mit meinen körperlichen Unvollkommenheiten gut leben.	❑	❑	❑	❑	❑
6.	Mir ist mein Körper oft lästig.	❑	❑	❑	❑	❑
7.	Ich fühle mich voller Kraft.	❑	❑	❑	❑	❑
8.	Mit meiner Figur bin ich unzufrieden.	❑	❑	❑	❑	❑
9.	Oft spüre ich mich voll erotischer Spannung.	❑	❑	❑	❑	❑
10.	Ich wünsche mir einen anderen Körper.	❑	❑	❑	❑	❑

		trifft nicht zu	trifft kaum zu	trifft teil-weise zu	trifft weit-gehend zu	trifft völlig zu
11.	Manchmal verspüre ich Ekel mir selbst gegenüber.	❑	❑	❑	❑	❑
12.	Ich habe genügend kraftvolle Spannung in mir.	❑	❑	❑	❑	❑
13.	Auf Fotos gefalle ich mir nicht.	❑	❑	❑	❑	❑
14.	Ich fühle mich topfit.	❑	❑	❑	❑	❑
15.	Meine körperlichen Mängel stören mich schon sehr.	❑	❑	❑	❑	❑
16.	Mit meinen sexuellen Wünschen beschäftige ich mich gerne.	❑	❑	❑	❑	❑
17.	Ich traue mir körperlich einiges zu.	❑	❑	❑	❑	❑
18.	Manchmal wünsche ich mir, völlig anders auszusehen.	❑	❑	❑	❑	❑
19.	Ich fühle mich in meinem Körper zu Hause.	❑	❑	❑	❑	❑
20.	Ausgelassen zu tanzen macht mir großen Spaß.	❑	❑	❑	❑	❑

BRIEF HOSPICE INVENTORY

Brief Hospice Inventory has been developed by Charles C. Cleeland. Original instrument has been published in English. The Brief Hospice Inventory, developed for use in hospice patients. There are four subscale; physical, psychological, patient's perception for hospice care, and quality of life.

Abbreviated Name: BHI
Author(s): Charles C. Cleeland
Purpose: To assess outcomes of hospice patients
Population: Terminal patients
Type of Instrument: Quality of Life
Mode of Administration:

Rater:	Self-administered
Time required:	9 minutes
Response Options:	10-point Likert scale
Scoring:	The form exists in a patient and caregiver versions, with a symptom subscale (8 items), and a quality-of-life subscale (9 items) scored on a 0 to 10 scale, with 0-4 as "mild", 5-6 as "moderate" and as 7-10 "severe".
Score Direction:	Higher scores show better QoL

Number of Items: 17
Original Language: English

Contact for information and permission to use:

Charles C. Cleeland
Department of Symptom Research
Box 221
The University of Texas
M. D. Anderson Cancer Center
1515 Holcombe Blvd, Houston, TX 77030 USA
E-mail: ccleeland@mdanderson.org

Dimensions covered by the questionnaire :

- Physical symptom
  - Pain
  - Tiredness
  - Nausea
  - Loss of apetite
  - Shortness of breath
- Psychological symptom
  - Depression
  - Anxiety
  - Distress related to changes in self care ability
- Patient's perception of hospice care
  - Overall symptom management
  - Sense of being cared for
  - Helpfulness of hospice care
- Quality of life
  - Pertaining to comfort
  - Feelings of life as a gift

Key References:

1. Guo H, Fine PG, Mendoza TR, Cleeland CS. A preliminary study of the utility of the brief hospice inventory. J Pain Symptom Manage 2001;22:637-48.

The increasing number of palliative care patients necessitates a simple, reliable instrument to routinely measure outcomes among hospice patients. We tested the utility of the Brief Hospice Inventory (BHI) to assess outcomes of hospice patients and estimations of patients' outcomes by nurse caregivers. In a prospective study, 145 home-based hospice patients were enrolled in the study from VistaCare Hospice. During the first week of admission, patients and nurse caregivers completed the BHI, which assessed patients' symptoms, satisfaction with care, and quality of life. Factor analysis supported a two-factor structure for the BHI for patients and caregivers, including a symptom subscale and quality of life subscale. Patients with severe symptoms showed improvement on the symptom subscale, but not the quality of life subscale, during the first 2 weeks after admission. The BHI shows utility in measuring hospice patients' symptom severity and quality of life over time.

BRIEF HOSPICE INVENTORY

1.	No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
2.	Not Tired	0	1	2	3	4	5	6	7	8	9	10	As Tired as Possible
3.	No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
4.	Not Depressed	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
5.	No Anxiety	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
6.	Best Possible Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Appetite
7.	No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
8.	Changes in my ability to care for myself cause: No Distress	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Distress
9.	To me, the last few days have been: A Gift	0	1	2	3	4	5	6	7	8	9	10	A Burden
10.	Over the last few days I have experienced: Complete Comfort	0	1	2	3	4	5	6	7	8	9	10	No Comfort at All
11.	Over the past few days I have felt: Completely Cared For	0	1	2	3	4	5	6	7	8	9	10	Not Cared for at All
12.	My quality of life is currently: Best Possible	0	1	2	3	4	5	6	7	8	9	10	Worst Possible
13.	My symptoms are: Completely Under Control	0	1	2	3	4	5	6	7	8	9	10	Completely Out of Control
14.	I feel completely: Satisfied in My Relationships	0	1	2	3	4	5	6	7	8	9	10	Unsatisfied in My Relationships
15.	Life has: More Meaning Than Ever	0	1	2	3	4	5	6	7	8	9	10	Lost All Its Meaning
16.	Hospice has been of: Greater help Than I Could Have Imagined	0	1	2	3	4	5	6	7	8	9	10	No Help at All
17.	My main goal for last week (if given) has: Been Completely Met	0	1	2	3	4	5	6	7	8	9	10	Not Been Met at All

*The Caregiver Survey only differs in that it presents queries in reference to the caregiver's perception of the patient's experience.

CDC HEALTH-RELATED QUALITY OF LIFE MEASURE-14[1]

In public health and in medicine, the concept of health-related quality of life (HRQOL) refers to a person or group's perceived physical and mental health over time. Physicians have often used HRQOL to measure the effects of chronic illness in their patients to better understand how an illness interferes with a person's day-to-day life. Similarly, public health professionals use health-related quality of life to measure the effects of numerous disorders, short- and long-term disabilities, and diseases in different populations. Tracking health-related quality of life in different populations can identify subgroups with poor physical or mental health and can help guide policies or interventions to improve their health.

The standard 4-item set of Healthy Days core questions (CDC HRQOL-4) has been in the State-based Behavioral Risk Factor Surveillance System (BRFSS) since 1993. Since 2000, the CDC HRQOL-4 has been in the National Health and Nutrition Examination Survey (NHANES) for persons aged 12 and older. Since 2003, the CDC HRQOL-4 has been in the Medicare Health Outcome Survey (HOS)—a NCQA HEDIS measure. Standard Activity Limitation and Healthy Days Symptoms modules have also been available since January 1995. When used together, these measures comprise the full CDC HRQOL-14 Measure.

CDC HRQOL-14 includes the four core questions, and ten additional questions about HRQOL. These questions ask about recent pain, depression, anxiety, sleeplessness, vitality, and the cause, duration, and severity of a current activity limitation an individual may have in his or her life.

Abbreviated Name: CDC-HRQOL14
Author(s): Centers for Disease Control and Prevention
Purpose: Developed for monitoring population health levels in support of epidemiologic and prevention research. Useful for the identification of health disparities, population trends, and identifying unmet health needs.
Population: Adult
Age Range : 18 to 99+
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Interviewer/ Telephone-administered
Time required:	3 minutes
Response Options:	Continuous open ended
Scoring:	Global score: Min score: 0 unhealthy days (healthy days = 100%) / Maximum score: 30 unhealthy days (healthy days = 0%) Scores by dimension : recent physical health recent mental health recent activity limitation Scores by items : recent pain recent depression recent anxiety recent sleeplessness recent vitality
Score Direction:	Higher scores show better QoL (evident from each measure) / Lower scores show better QoL (evident from each measure)

Number of Items: 14
Original Language: English
Existing Translations : Spanish

[1] U.S. Dept. of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Adult and Community Health

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Contact for information and permission to use:

Rosemarie Kobau, MPH
Public Health Advisor
CDC, NCCDPHP, DACH
Health Care & Aging Studies Branch
Tel: 770/488-6087
Fax: 770/488-5486
E-mail: RKobau@cdc.gov

Dimensions covered by the questionnaire :

- Physical health (2 items)
- Mental health (4 items)
- Activity limitation (6 items)
- General health status (1 item)
- Pain (1 item)
- Vitality (1 item)
- Rest / Sleep (1 item)

Key References:

1. Centers for Disease Control and Prevention. Measuring Healthy Days: Population Assessment of Health-Related Quality of Life. Atlanta, Georgia: November, 2000

1

Health-Related Quality-of-Life Measure (HRQOL-14)

Health Care and Aging Studies Branch
Division of Adult and Community Health
National Center for Chronic Disease Prevention and Health Promotion
Centers for Disease Control and Prevention

The 4-item set of health-related quality-of-life questions (HRQOL-4) below has been in continuous use in the state-based Behavioral Risk Factor Surveillance System (BRFSS) since January, 1993 (See www.cdc.gov/nccdphp/brfss/). As of the end of 1999, over 800,000 adults aged 18 and older have responded to these core BRFSS questions. Beginning in 2000, the HRQOL-4 are also asked in the National Health and Examination Survey (NHANES) for persons aged 12 and older. A related 10-item Quality-of-Life (QOL) module has also been available for optional use in the BRFSS since January 1995. When used together, the HRQOL-4 and the supplemental 10-item module form the expanded HRQOL-14 set of questions that many states and communities are now using in their surveys, providing a large public-domain source of HRQOL population data.

The CDC HRQOL-14 questions have been validated in several studies, including ones that have cross-validating the questions with the widely-used Rand Corporation's Medical Outcomes Study Short-Form 36 (SF-36). Results to date indicate that the HRQOL-14 questions, in spite of their brevity, predict short-term mortality and hospital utilization and have reasonably good criterion validity with respect to the SF-36 in both healthy and disabled populations. The BRFSS QOL questions significantly extend the utility of the BRFSS, now administered and used by all 50 states and the District of Columbia.

The interview will only take a short time, and all the information obtained in this study will be confidential.

Section 1: Health Status

1. Would you say that in general your health is: (33)

	Please Read	
	a. Excellent	1
	b. Very good	2
	c. Good	3
	d. Fair	4
	or	
	e. Poor	5
Do not read these responses	Don't know/Not sure	7
	Refused	9

2. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good? (34-35)

a. Number of days	_ _
b. None	88
Don't know/Not sure	77
Refused	99

3. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good? (36-37)

a. Number of days	_ _
b. None **If Q. 2 also "None," skip next question**	88
Don't know/Not sure	77
Refused	99

4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation? (38-39)

a. Number of days	_ _
b. None	88
Don't know/Not sure	77
Refused	99

Supplemental Quality-of-Life Module

These next questions are about physical, mental, or emotional problems or limitations you may have in your daily life.

1. Are you LIMITED in any way in any activities because of any impairment or health problem?
   - a. Yes 1
   - b. No **Go to Q. 6** 2
   - Don't know/Not sure **Go to Q. 6** 7
   - Refused **Go to Q. 6** 9

2. What is the MAJOR impairment or health problem that limits your activities?
   Do Not Read. Code Only One Category.
   - a. Arthritis/rheumatism 0 1
   - b. Back or neck problem 0 2
   - c. Fractures, bone/joint injury 0 3
   - d. Walking problem 0 4
   - e. Lung/breathing problem 0 5
   - f. Hearing problem 0 6
   - g. Eye/vision problem 0 7
   - h. Heart problem 0 8
   - i. Stroke problem 0 9
   - j. Hypertension/high blood pressure 1 0
   - k. Diabetes 1 1
   - l. Cancer 1 2
   - m. Depression/anxiety/emotional problem 1 3
   - n. Other impairment/problem 1 4
   - Don't know/Not sure 77
   - Refused 99

3. For HOW LONG have your activities been limited because of your major impairment or health problem?
   Do Not Read. Code using respondent's unit of time.
   - a. Days 1 _ _
   - b. Weeks 2 _ _
   - c. Months 3 _ _
   - d. Years4 _ _
   - Don't know/Not sure 7 7 7
   - Refused 9 9 9

4. Because of any impairment or health problem, do you need the help of other persons with your PERSONAL CARE needs, such as eating, bathing, dressing, or getting around the house?
   - a. Yes 1
   - b. No 2
   - Don't know/Not sure 7
   - Refused 9

5. Because of any impairment or health problem, do you need the help of other persons in handling your ROUTINE needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?
   - a. Yes 1
   - b. No 2
   - Don't know/Not sure 7
   - Refused 9

6. During the past 30 days, for about how many days did PAIN make it hard for you to do your usual activities, such as self-care, work, or recreation?
   a. Number of days _____ _ _
   b. None 8 8
   Don't know/Not sure 7 7
   Refused 9 9

7. During the past 30 days, for about how many days have you felt SAD, BLUE, or DEPRESSED?
   a. Number of days _____ _ _
   b. None 8 8
   Don't know/Not sure 7 7
   Refused 9 9

8. During the past 30 days, for about how many days have you felt WORRIED, TENSE, or ANXIOUS?
   a. Number of days _____ _ _
   b. None 8 8
   Don't know/Not sure 7 7
   Refused 9 9

9. During the past 30 days, for about how many days have you felt you did NOT get ENOUGH REST or SLEEP?
   a. Number of days _____ _ _
   b. None 8 8
   Don't know/Not sure 7 7
   Refused 9 9

10. During the past 30 days, for about how many days have you felt VERY HEALTHY AND FULL OF ENERGY?
    a. Number of days _____ _ _
    b. None 8 8
    Don't know/Not sure 7 7
    Refused 9 9

CHILD HEALTH QUESTIONNAIRE

The Child Health Questionnaire™ (CHQ) is a family of generic quality of life instruments that have been designed and normed for children 5-to-18 years of age. The CHQ measures 14 unique physical and psychosocial concepts. The parent form is available in 2 lengths - 50 or 28 items. Scores can be analyzed separately, the CHQ Profile Scores, or combined to derive an overall physical and psychosocial score, the CHQ Summary Scores. The CHQ Manual includes copies of the forms and SAS scoring. SPSS code is provided upon written request.

In the United States, normative values and benchmarks for the parent-reported versions of the CHQ are available for some conditions. The CHQ has been extensively translated using rigorous international guidelines. The youth version is 87 items. Authorized translations are available from HealthActCHQ. Norms, benchmarks, and summary scoring for the youth version will be forthcoming upon the development and testing of a short-form by the Principal Developer.

Abbreviated Name: CHQ
Author(s): Jeanne M. Landgraf, John E. Ware, Jr.
Purpose: To assess health related quality of life in children
Population: Pediatrics
Age Range : 5+ years children
Type of Instrument: Symptom/Functioning
Mode of Administration: Self- or Proxy-administered

Rater:	Self-/ Proxy-administered
Time required:	8 minutes for the Parent form, 20 minutes for the Child form
Response Options:	Yes/No and Likert scale
Scoring:	Global score Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: Parent Form: For parents of children 5 - 17 years of age: 50 items (28 for the Short Form)
Youth Form: 87 items
Original Language: English
Existing Translations : Argentinian, Australian, Bulgarian, Chilean, Chinese (Singaporean), Costa Rican, Croatian, Czech, Danish, Dutch, Finnish, French, German, Georgian, Greek, Hebrew, Hungarian, Iberian, Italian, Korean, Latvian, Malaysian, Mexican, Norwegian, Polish, Portuguese, Russian, Serbian, Slovakian, Spanish, Swedish, Turkish, Yugoslavian.

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Contact for information and permission to use:

Jeanne M Landgraf
HealthActCHQ
8 Faneuil Hall 3rd Floor
Boston, MA 02109 USA
Telephone: 617.973.5111
Fax: 617.973.5112
E-mail: jml@healthact.com

Dimensions covered by the questionnaire :

Child/adolescents concepts:

- general health
- change in health
- physical functioning
- bodily pain/discomfort
- limitations in school, work, and activities with friends due to physical problems
- limitations in school, work, and activities with friends due to emotional difficulties
- limitations in school, work, and activities with friends due to behavioral difficulties
- behavior
- mental health
- self esteem

Parent/family concepts :

- emotional and time impact on the parent
- limitations in family activities
- family cohesion

Existence of a scoring/interpretation/user manual : Yes

Key References:

1. Landgraf JM. Measuring Pediatric Outcomes in Applied Clinical Settings: an Update about the Child Health Questionnaire (CHQ). Quality of Life Newsletter 1999;23:5-6

Children are often silent participants in health care. They rely on parents and others to advocate for their well being. While growth and physical development are of principal concern, children's emotional and social maturation and its impact on the quality of everyday life at home and at school are equally tantamount. Until as recently as 1995, however, there were relatively few well-validated instruments that measured the quality of children's health and well being from this broad perspective. Fewer still were instruments that were practical and easily integrated into busy clinical practice.
The Child Health Questionnaire (CHQ) was developed and normed in the U.S. as part of a broad mission to enhance the voice of children and their families in the health care arena. The goal was to develop a comprehensive instrument that would be useful across a variety of healthcare settings and applications including academic research, clinical trials, physician offices, clinics, hospitals and health maintenance organizations. After more than six years of industry-sponsored research the end result was development of the CHQ - a constellation of measures that share a common conceptual framework but vary in length and reporter (i.e. parent or child).

2. Landgraf, J.M. and Abetz, L. (1998). Influences of sociodemographic characteristics on parental reports of children's physical and psychosocial well-being: Early experiences with the Child Health Questionnaire (CHQ-PF50). Drotar, D. (ed.), Quality of Life Assessment in Children. New York: Lawrence Erlbaum Press (pp. 105-126).
3. Landgraf, J.M. and Abetz, L.N. The physical and psychosocial well-being of children representing three cultural groups: Initial self-reports using the Child Health Questionnaire (CHQ-CF87). Psychology and Health, Quality of Life: Recent Advances in Theory and Methods.1997;12:839-854.
4. Landgraf, J.M., Abetz, L., and Ware, J.E. (9-10 May 1996). Psychometric Results of the CHQ-PF50 Form in a Normative U.S. Sample of Children and Its Clinical Application Across

Several Condition Groups. Competitive paper presentation at the Third Annual Symposium of Contributed Papers, Quality of Life Evaluation, Boston MA.

5. Landgraf, J.M., Abetz, L. N., DeNardo, B. A., and Tucker, L. B. (1995). Clinical validity of the Child Health Questionnaire-Parent Form in children with rheumatoid arthritis. Poster presented at the 1995 National Scientific Meeting of the American College of Rheumatology, San Francisco, CA, October 21, 1995.
6. Landgraf JM, Abetz, L, and Ware JE. The CHQ User's Manual. First Edition. Boston, MA:The Health Institute, New England Medical Center.

SAMPLE ITEMS*

Child Health Questionnaire - Parent Report
CHQ-PF28

INSTRUCTI0NS-

1. This booklet asks about your child's health and well-being. Your Individual answers will not be shared with anyone.
2. If you choose not to participate It will not affect the care you receive.
3. Answer the questions by marking the appropriate box 12L
4. Certain questions may look alike but each one Is different Some questions ask about problems your child may not have. That's great, but it's Important for us to know. Please answer each question.
5. There are no right or wrong answers. If you are unsure how to answer a question, please give the best answer you can and make a comment In the margin.
6. All comments will be read, so please feel free to make as many as you wish.

Child Health Questionnaire - Parent Form 28 (CHO-PF28)
1991, 1996 0 Landgraf and Ware

* The CHQ, examples of the CHQ, are reprinted here with permission of the copyright holder. Information about the scales and their use can be obtained from HealthAct. Please address inquiries to: Dr. Jeanne M Landgraf, HealthActCHQ, Boston, MA 02109 USA. E-mail: jml@healthact.com and web address http://www.healthact.com. Readers of this compendium are also encouraged to visit the following website that contains additional information about the CHQ Scales: http://www.healthact.com/ Use of the CHQ Scales requires written permission and payment, in advance, of licensure fees.

SECTION 01: YOUR CHILD'S GLOBAL HEALTH

1.1. In general, would you say your child's health is:

Excellent **Very good** **Good** Fair **Poor**

SECTION #2: YOUR CHILD'S PHYSICAL ACTIVITIES

The following questions ask about physical activities your child might do during a day

2.1. During the last 4 weeks, has your child been limited in any of the following activities due to health problems?

		Yes, limited a lot	Yes, limited some	Yes, limited a little	No, not limited
a.	Doing things that take a lot of energy, such as playing soccer or running?	0	0	0	0
b.	Doing things that take some energy such as riding a bike or skating?	0	0	0	0
c.	Bending, lifting, or stooping?	0	0	0	0

SECTION 03: YOUR CHILD'S EVERYDAY ACTIVITIES

3.1. During the past 4 weeks, has your child been limited in the AMOUNT of time he/she could spend on schoolwork or activities with friends due to EMOTIONAL difficulties or problems with his/her BEHAVIOR?

0	**0**	**0**	**0**
Yes, limited a lot	**Yes, limited some**	**Yes, limited a little**	**No, not limited**

3.2. During the past 4 weeks has your child been limited in the KIND of schoolwork or activities he/she could do with friends due to problems with his/her PHYSICAL health?

0	**0**	**0**	**0**
Yes, limited a lot	**Yes, limited some**	**Yes, limited a little**	**No, not limited**

Child Health Questionnaire - Parent Form 28 (CHO-PF28)
1991, 1996 0 Landgraf and Ware

SECTION #6: GENERAL VVELL-BEING

6.1. During the past 4 weeks, how much of the time do you think your child:

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. felt lonely?	0	0	0		0
b. acted nervous?		0	0		0
c. acted bothered or upset?		0	0	,,,	0

SECTION X7: SELF-ESTEEM

The following ask about your child's satisfaction with self, school, and others. It may be helpful If you keep In mind how other children your child's age might feel about these areas.

7.1. During the past 4 weeks, how satisfied do you think your child has felt about:

	Very Satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Very dissatisfied
a. his/her school ability?					
b. his/her friendships?					
c. his/her life overall?					

SECTION #8: YOUR CHILD'S HEALTH

8.1. How true or false Is the statement for your child? **Options** (definitely true, mostly true, don't know, mostly false, definitely false)

a. My child seems to be less healthy than other children I know.
b. My child has never been seriously ill.
c. I worry about my child's health more than other people worry about their children's health.

8.2. Compared to one year ago, how would you rate your child's health now:

0	0	0	0	0
Much better now than 1 year ago	Somewhat better now than 1 year ago	About the same now as 1 year ago	Somewhat worse now than 1 year ago	Much worse now than I year ago

Child Health Questionnaire - Parent Form 28 (CHQ-PF28)
1991, 1996 0 Landgraf and Ware

11.5 Have you ever been told by a teacher. school official. doctor, nurse or other health professional that your child has any of the following conditions?

	Yes	No
a. anxiety problems		
b. asthma		
c. attentional problems		
d. behavioral problems		
e. chronic allergies or sinus trouble		
f. chronic orthopedic, bone or joint problems		
g. chronic respiratory, lung or breathing trouble (NOT ASTHMA)		
h. chronic rheumatic disease		
i. depression		
j. developmental delay or mental retardation		
k. diabetes		
l. epilepsy (seizure disorder)		
m. hearing impairment or deafness		
n. learning problems		
o. sleep disturbance		
p. speech problems		
q. vision problems		
r. does your child have any other chronic medical condition that is affecting what they do or how they feel? (Please describe below)		

Child Health Questionnaire - Parent Form 28 (CHO-PF28)
1991, 1996 0 Landgraf and Ware

Child Health Questionnaire Parent Form 50 Questions (Samples)

In general, how would you rate your child's health?
Has your child been limited in any of the following activities due to health problems

- doing things that take a lot of energy, such as playing soccer or running; doing things that take some energy such as riding a bike or skating; ability (physically) to get around the neighborhood, playground, or school; walking one block or climbing one flight of stairs; bending, lifting,/stooping; taking care of him/herself?

Has your child's school work or activities with friends been limited in any of the following ways due to emotional difficulties or problems with his/her behavior

- limited in the kind of schoolwork or activities with friends he/she could do; limited in the amount of time he/she could spend on schoolwork or activities with friends; limited in performing schoolwork or activities with friends?

Has your child's school work or activities with friends been limited in any of the following ways due to problems with his/her physical health

- limited in the kind of schoolwork or activities with friends he/she could do; limited in the amount of time he/she could spend on schoolwork or activities with friends?

How much bodily pain or discomfort has your child had?
How often has your child had bodily pain or discomfort?
How often did each of the following statements describe your child

- argued a lot; had difficulty concentrating or paying attention; lied/cheated; stole things; had tantrums?

Compared to other children your child's age, in general how would you rate his/her behavior?
How much of the time do you think your child:

- felt like crying; felt lonely; acted nervous; bothered or upset; cheerful?

How satisfied do you think your child has felt about:

- his/her school ability; athletic ability; friendships; looks/appearance; family relationships; life overall?

My child seems to be less healthy than other children I know;

- My child has never been seriously ill; When there is something going around my child usually catches it; I expect my child will have a very healthy life; I worry more about my child's health than other people.

Compared to one year ago, how would you rate your child's health now?
How much emotional worry or concern did each of the following cause you

- your child's physical health; emotional well-being or behavior; attention or learning abilities?

Were you limited in the amount of time you had for your own needs because of your child's

- physical health; emotional well-being or behavior; attention or learning abilities?

How often has your child's health or behavior

- limited the types of activities you could do as a family; interrupted various everyday family activities; limited your ability as a family to "pick up and go"; caused tension or conflict; been a source of disagreements or arguments in your family; caused you to cancel or change plans (personal or work) at the last minute?

In general, how would you rate your family's ability to get along with one another?

Child Health Questionnaire Child Form 87 Questions (Samples)

In general, how would you say your health is?
Has it been difficult for you to do the following activities due to health problems

- doing things that take a lot of energy, such as playing soccer or running; doing things that take some energy such as riding a bike or skating; walk several blocks or climb several flights of stairs; ability (physically) to get around the neighborhood, playground, or school; walk one block or climbing one flight of stairs; do your tasks around the house; bend, lift or stoop; eat, dress, bathe or go to the toilet by yourself; get in/out of bed?

Has it been difficult to do certain kinds of schoolwork or activities with friends because of problems like feeling sad or worried;

- spend the usual amount of time on schoolwork or activities with friends; get schoolwork done at all or do any activities with friends?

Has it been difficult to do certain kinds of schoolwork or activities with friends because of problems with your behavior;

- spend the usual amount of time on schoolwork or activities with friends; get schoolwork done at all or do any activities with friends?

Has it been difficult to do certain kinds of schoolwork or activities with friends because of problems with your physical health;

- spend the usual amount of time on schoolwork or activities with friends; get schoolwork done at all or do any activities with friends?

How much bodily pain or discomfort have you had?
How often have you had bodily pain or discomfort?
How often did each of the following statements describe you ñ acted to young for your age;

- argued; had a hard time paying attention; did not do what your teacher or parent asked you to do; wanted to be alone; lied/cheated; had a hard time getting others to like you; felt clumsy; ran away from home; had speech problems; stole things at home or outside the home; acted mean or moody if you did not get what you wanted; got really mad when you did not get what you wanted; found it hard to be with others; had a hard time getting along with others.

Compared to other children your age, in general how would you rate your behavior?
How much of the time do you:

- feel sad; feel like crying; feel afraid or scared; worry about things; feel lonely; feel unhappy; feel nervous; feel bothered or upset; feel happy; feel cheerful; enjoy the things you do; have fun; feel jittery or restless; have trouble sleeping; have headaches; like yourself?

How good or bad have you felt about:

- yourself; your school work; your ability to play sports; your friendships; the things you can do; the way you get along with others; your body and your looks; the way you seem to feel most of the time; the way you get along with your family; the way life seems to be for you; your ability to be a friend to others; the way others seem to feel about you; your ability to talk with others; your health in general?

My health is excellent;

- I was so sick once I thought I might die; I do not seem to get very sick; I seem to be less healthy than other kids I know; I have never been very, very sick; I always seem to get sick; I think I will be less healthy when I get older; I think I will be very healthy when I get older; I never worry about my health; I think I am healthy now; I think I worry more about my health than other kids my age.

Compared to one year ago, how would you rate your health now?

How often has your health or behavior - limited the types of activities you could do as a family;

- interrupted various everyday family activities; limited your ability as a family to "pick up and go"; caused tension or conflict; been a source of disagreements or arguments in your family; caused your family to cancel or change plans at the last minute?

In general, how would you rate your family's ability to get along with one another?

CLIENT SATISFACTION QUESTIONNAIRE

The Client Satisfaction Questionnaire© (CSQ) was developed at the University of California San Francisco (UCSF) by Drs. Clifford Attkisson and Daniel Larsen in collaboration with Drs. Willian A. Hargreaves, Maurice LeVois, Tuan Nguyen, Robert E. Roberts, and Bruce Stegner. Since 1975, a team of investigators at the University of California San Francisco (UCSF) has employed standard scale development methods to construct the CSQ and other instruments by synthesizing related literature.

CSQ scales are used in a wide range of clinical and human services as well as services research and health policy studies. The CSQ instruments are self-report questionnaires constructed to measure general satisfaction with services received by individuals and families.

Abbreviated Name: CSQ (CSQ-31, CSQ-18A, CSQ-18B, CSQ-8)
Short versions: CSQ-4, CSQ-3
Author(s): C. Clifford Attkisson & Daniel Larsen
Purpose: To assess general medical illness, mental health services, preventive services, and the general array of human services.
Population: Adult
Type of Instrument: Satisfaction
Mode of Administration: Self-administered

Rater:	Self-administered
Time required:	5-10 minutes
Response Options:	Likert scale
Scoring:	Global score
	Scores by dimension
Score Direction:	Higher scores show better QoL (evident from each measure)

Number of Items: 31, 18, 8, 4 or 3
Original Language: English
Existing Translations :
CSQ-8: Arabic, Cambodian, Chinese, Dutch, French, Japanese, Korean, Laotian, Portuguese, Russian, Spanish, Tagalog, Vietnamese.
CSQ-18B: French, Portuguese

The CSQ Scales are copyrighted © (Attkisson, 1979, 1989, 1990) and can be used by permission only. There is a cost per use and modifications of the instrument items, scale format, or text are not permitted.

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Contact for information and permission to use:

Clifford Attkisson, Ph.D.
Professor of Medical Psychology
Child Services Research Group
University of California
1388 Sutter Street, Suite 503
San Francisco, CA 94109
Phone: 415-476-7713
Fax: 415-502-6177
E-Mail: clifford.attkisson@ucsf.edu
http://saawww.ucsf.edu/csq/
http://saawww.ucsf.edu/attkisson/

Dimensions covered by the questionnaire :

- Physical surroundings
- Procedures
- Support staff
- Kind / Type of service
- Treatment staff
- Quality of service
- Amount, Length or Quantity of service
- Outcome of service
- General satisfaction

Key References:

1. Attkisson CC, Greenfield TK. The UCSF Client Satisfaction scales: I. The Client Satisfaction Questionnaire-8. In M.E. Maruish (Ed.), The use of psychological testing for treatment planning & outcome assessment 1999; 2nd ed., p.1333-1346. Hillsdale, New Jersey: Lawrence Erlbaum Associates, Publishers.
2. Attkisson CC, Greenfield TK. The Client Satisfaction Questionnaire (CSQ) scales. In L.L. Sederer & B. Dickey (Eds.), Outcome assessment in clinical practice 1996 p.120-127. Baltimore, MD: Williams & Wilkins.
3. Attkisson CC, Greenfield TK. Client Satisfaction Questionnaire-8 and Service Satisfaction Scale-30. In M.E. Maruish (Ed.), The use of psychological testing for treatment planning & outcome assessment, 1994;p.402-420. Hillsdale, New Jersey: Lawrence Erlbaum Associates, Publishers.
4. Attkisson CC, Zwick R. The Client Satisfaction Questionnaire: Psychometric properties and correlations with service utilization and psychotherapy outcome. Evaluation and Program Planning 1982; 5:233-237

An 18-item version of the Client Satisfaction Questionnaire (CSQ-18) was included in an experimental study of the effects of pretherapy orientation on psychotherapy outcome. The psychometric properties of the CSQ-18 in this study were compared with earlier findings. In addition, the correlations of the CSQ-18 with service utilization and psychotherapy outcome measures were examined. Results indicated that the CSQ-18 had high internal consistency (coefficient alpha = .91) and was substantially correlated with remainer-terminator status (rs = .61) and with number of therapy sessions attended in one month (r = .54). The CSQ-18 was also correlated with change in client-reported symptoms (r = -.35), indicating that greater satisfaction was associated with greater symptom reduction. Results also demonstrated that a subset of items from the scale (the CSQ-8) performed as well as the CSQ-18 and often better. The excellent performance of the CSQ-8, coupled with its brevity, suggests that it may be especially useful as a brief global measure of client satisfaction.

5. Larsen DL, Attkisson CC, Hargreaves WA, Nguyen TD. Assessment of client/patient satisfaction: Development of a general scale. Evaluation and Program Planning, 1979; 2: 197-207.

THE CLIENT SATISFACTION QUESTIONNAIRE (CSQ) SCALES AND SERVICE SATISFACTION SCALES (SSS): A HISTORY OF MEASURE DEVELOPMENT AND A GUIDE FOR USERS

C. Clifford Attkisson, Ph.D., Thomas K. Greenfield Ph.D., and Diane Melendez, Ph.D.
Department of Psychiatry. University of California San Francisco

GENERAL CONSIDERATIONS IN USE OF THE SATISFACTION SCALES

Instructions for Scale Completion

Standard written instructions to respondents using the CSQ scales state:
"Please help us improve our program by answering some questions about the services you have received. We are interested in your honest opinions, whether they are positive or negative. Please answer all the questions. We also welcome your comments and suggestions. Thank you very much, we really appreciate your help."

Items follow, immediately, such as:
"How would you rate the quality of service you have received?"
At the end of the CSQ items, service recipients are thanked and invited to give additional open-ended comments:
"The thing I have liked best about my experience here is . . . What I liked least was . . . If I could change one thing about the service it would be. . ."

Application

The primary use of the CSQ scales, within clinical and practice settings, is to assess the aggregate satisfaction of groups of respondents and only rarely is the focus on the individual service recipient or surrogate. Thus, while satisfaction scores have sometimes been treated as a measure of individual-level outcome, the usual application is to measure aggregate satisfaction levels of a group of consumers. The satisfaction scores have typically been employed as outcome performance indicators for a service organization, clinic, or system of care. In these instances, it is critical to compare obtained scale scores (usually raw scale totals summed across all items and/or the mean of item means) against comparative norms from other service settings or from other time frames within the same setting. Using concurrent and repeated sampling methods, satisfaction levels can be compared across different service modalities, duration of service, types of clients, providers, or specific facilities. In using any consumer satisfaction measure, perhaps the most important validity consideration is designing procedures to obtain high response rates to minimize biases attributable to non response (Greenfield & Attkisson, 1989; Nguyen, Attkisson, & Stegner, 1983).

Scale Administration and Sampling Strategies

Major goals of administration procedures are to ensure the highest possible response rate in order to minimize bias due to nonresponse (Attkisson & Greenfield, 1994) in addition to minimizing bias from other sources such as demand characteristics, wish to please or fears of displeasing “authorities”. The most rigorous and careful administration techniques have been employed during the analyses of scale performance for the English and other language versions. Mail survey methods (either mail-out and prepaid mail-back, or hand-out and mail-back) have sometimes been used for collecting the data (Kurtz, 1990), but may result in low response rate. From 40% to 50% is typically the highest response rate achieved, even with one follow-up postcard reminder. (e.g., Greenfield, 1983). In one study different techniques for administering the SSS-30 were compared and resulted in large variations in response rates by method Nebeker (1992) and see (Attkisson & Greenfield, 1994). For example, staff administration of the scales at two sites resulted in low response rates, i.e., 41% and 20% (ns = 50 each) (Nebeker, 1992 cited in Attkisson & Greenfield, 1994, p. 404). In comparison, a "group momentum" technique in which the staff and researcher explained the study, encouraged participation, and then allowed clients to complete the questionnaire anonymously resulted in a high response rate (97%) (Nebecker, cited in Attkisson & Greenfield 1994).

The recommended approach in outpatient settings is to use point of service or waiting room surveys with a designated scale administrator or a receptionist trained in procedures for systematically soliciting voluntary participation from sampled clients. Providing standard instructions emphasizing, as well, the need for "your candid opinions" so as to improve the services, while assuring the respondent of anonymity and confidentiality, is very important.

Various sampling schemes have been used including systematic or random samples of client rosters, samples stratified by duration or quantity of services received, and census samples of all clients served during a time period (Attkisson & Greenfield, 1994; Greenfield & Attkisson, 1989). The latter approach, provided that the time frame is at least two typical service weeks, has the advantage of assuring that few clients are omitted (only those missing appointments throughout the whole period, or those declining to participate). Completion rates tend to be above 90% when this approach is used.

The practical problem of surveying satisfaction at increasing time intervals after termination is the expected attenuation in response rate due to location problems and declining interest, among others, which is likely to confound interpretation of results. Most studies have used anonymous methods though some have not, and have included code numbers allowing linkage to service data and potential for targeted follow up of non responders in an attempt to "convert" them, either by telephone or further mailings. One methodological study with the CSQ found optional identified (the name of the counselor and of the therapist written in at the option of the recipient) forms did not result in lower response rate or higher reported satisfaction (Greenfield, 1983). Despite the range of alternative approaches, the standard waiting room method meets well the simplicity and uniformity of implementation criterion in most outpatient settings and may be adapted to residential settings equally well (Nebeker, 1992).

Scoring

Scoring the closed-ended part of the CSQ and the SSS-30 scales involves: (a) unweighted summation of the direction-corrected response values (1–4 for all the CSQ scales and 1–5 for the SSS-30) for the total scales; and (b) calculation of measures of central tendency and distribution (such as mean, standard deviation, median, and mode) of the individual item ratings, for the total scale scores, and or for the factor scores (SSS-30) (2). Scoring is not complicated and involves calculation of total score across all items for each subject and analyzing item and total score/substance distributions across groups of subjects. Because of the scale's single factor structure, interpretation of CSQ-8 data involves a straightforward comparison of results obtained for a given service or client group with external data that constitute an appropriate norm, e.g., the multi-service setting means and standard deviation results presented in Nguyen et al. (1983). In contrast, factor scores can be calculated for the SSS scales (Greenfield & Attkisson, 1989) which are also best referred to published norms (Attkisson & Greenfield, 199A and see here in [Tables]).

Automation

Several computer scoring systems are available for use with the CSQ scales. All scanning applications used with the CSQ and SSS scales must have prior permission from the authors as such automation requires use and modification of the authors' intellectual property. Information about commercial firms offering these services is available from the authors.

Permission to Use

Written permission is required for use of the CSQ and SSS-30 scales and use is strictly limited to individuals and institutions who formally request permission directly from the authors or are licensed to use the instruments through commercial firms having non-exclusive agreements with the authors. Prior written permission and payment of "per use" fees are required of all users. Prices are available from the authors and are subject to change to accommodate price increases for related supplies and materials. Specific inquiries and requests to use the scales must be addressed to the authors and sent via mail services or by facsimile (see below for numbers). Response to initial inquiry is rapid and includes a current price schedule and reprints of basic published materials on the scales. Inquiries regarding the CSQ family of scales should be addressed to Dr. Attkisson (fax: 415-476-9690) and inquiries about the SSS scales should be addressed to Dr. Greenfield (fax: 510-642-7175).

The authors frequently receive requests for permission to modify the wording of scale items. Permission is never granted since such changes infringe on intellectual property of the authors, void or limit the normative comparisons available in the published literature, and may have significant effects on the psychometric performance of the items, scale factors, and the overall integrity of the scales. Instead users are asked to create their own site-specific items, if they deem it necessary to do so, and administer them separately ideally following the standard scale(s), perhaps as a part of a battery of measures.

DEVELOPMENT OF CONSUMER SATISFACTION SCALES AT UCSF

Initial CSQ Scale Development Research

Development of client satisfaction measures at UCSF involved a series of studies using versions of a general satisfaction measure, the Client Satisfaction Questionnaire (CSQ). Using a logic model, items were drawn from a large pool of items written by Larsen et al. (1979) covering nine conceptual domains of client satisfaction: Physical Surroundings; Procedures; Support Staff; Kind/type of Service; Treatment Staff; Quality of Service; Amount, Length, or Quantity of Service; Outcome of Service; and General Satisfaction. Factor and item analyses, conducted across a series of studies, resulted in several unidimensional measures — each having somewhat different applied utility. In addition to an eight-item version, called the CSQ-8 (Nguyen et al., 1983), the most widely used short measure, alternate forms based on the CSQ-31 were constructed, each containing 18 items (LeVois et al., 1981). These two parallel 18-item forms (the CSQ-18A and CSQ-18B) are suitable for test-retest applications. Form B of the CSQ-18 includes the CSQ-8 items. Finally, shorter versions have been employed for applications in which a very brief indicator is required (e.g., the CSQ-4, Greenfield, 1983; or the CSQ-3, Larsen et al., 1979). All CSQ scales have very high levels of internal consistency (see Table 1) and generally measure a single, underlying global satisfaction factor.

The CSQ-8, (Nguyen et al., 1983) has received frequent citation in the scientific and professional literature and has been adopted extensively for applied use within service settings and in research. The CSQ-8 is an 8-item short form of the 31-item instrument (CSQ-31) initially published by Larsen, Attkisson, Hargreaves, and Nguyen (1979). Because of its strong psychometric properties, for most purposes this shorter scale, the CSQ-8, substitutes well for the full instrument. The efficient CSQ-8 has had widespread use in many types of human service settings. The primary norm group for the CSQ-8 is 3,120 clients of 76 collaborating clinical facilities within 21 community mental health centers in the (predominantly Western) U.S. Most (81.5%) of the sample were outpatients, in 41 different clinics; the others were drawn from 4 psychiatric inpatient, 11 residential, and 20 partial care settings (Nguyen et al., 1983). In addition, UCSF investigators also studied the utility and psychometric properties of shorter 1-, 3-, and 4-item subsets of the CSQ-8.

Because of the scale's single factor structure, interpretation of CSQ-8 data involves a straightforward comparison of results obtained for a given service or client group with external data that constitute an appropriate norm, e.g., the multi-service setting means and standard deviation results presented in Nguyen et al. (1983). Care must be taken to standardize the method of administration. In addition, response sets of respondents must be carefully considered in the interpretation of findings.

Basic Validity and Reliability Studies of the English-language CSQ-8

The initial CSQ scale development research phase is documented in Patient satisfaction in health and mental health services (Attkisson & Pascoe, 1983). This compendium and several other contemporaneous publications by the UCSF group described experience bearing on the reliability and validity of the CSQ. This research documents and the scales' psychometric properties within various subpopulations and language groups. The various CSQ scales were found to have strong levels of internal consistency and consumer acceptability. Utility of consumer satisfaction measures in clinical and services research was also demonstrated and compared with other methods of assessing service satisfaction (Attkisson & Zwick, 1982; Attkisson, Roberts, & Pascoe, 1983; Pascoe & Attkisson, 1983; Pascoe, Attkisson, & Roberts, 1983; Pascoe, 1984). Psychometric results from 12 published studies are presented in Table 1

Psychometric Properties of the Client Satisfaction Questionnaire Scales (CSQ-8; CSQ-3/4) as Reported in Various Studies

Published Studies	Larsen et al. (1979)	Nguyen et al. (1983)	Attkisson et al. (1983)	Greenfield (1983)	Roberts & Attkisson (1983)
CSQ Scale Version	CSQ-8	CSQ-8	CSQ-8	CSQ-3/ CSQ-4	CSQ-8
Sample Size	n = 248	n = 3,120	n = 119	n = 1,267	n = 2,605
Sample Ethnicity	Diverse	Diverse	Diverse	Anglo	Anglo
Health Domain	Mental Health	Mental Health	Primary Care	Counseling	Mental Health
Total score: (Average)	(a)	27.09	(a)	9.95/13.52	27.23
(Standard Deviation)	(a)	4.01	(a)	2.02/2.52	3.95
Mean of Item means	(a)	3.39	3.68	(a)	3.40
Mean of Item variances	(a)	0.48	0.31	(a)	0.54
Coefficient alpha	0.93	0.87	0.83	.83/.86	0.88
Median Item-total (b) *r*	(a)	0.65	0.57	(a)	(a)
Minimum Item-total *r*	(a)	0.54	0.46	(a)	0.55
Maximum Item-total *r*	(a)	0.68	0.68	(a)	0.69
Mean Inter-Item *r*	(a)	0.47	0.40	(a)	0.48
Minimum Inter-Item *r*	(a)	0.35	0.25	(a)	0.37
Maximum Inter-Item *r*	(a)	0.65	0.69	(a)	0.66

(a)Data not available (b)Item-total correlations are corrected for the presence of the Item being evaluated. (c)Reported in Attkisson and Greenfield (1994,p. 407).

(d)Data are abstracted from the references cited in this table.

The various CSQ scales have been assessed in a variety of health, mental health, and human service sites including over 8000 subjects in the scale development and refinement phase. The CSQ-8 and the CSQ-18A and B have demonstrated very high levels of internal consistency as measured by Cronbach's alpha. Cronbach alpha coefficients have ranged from .83 to .93 across the 12 studies included in Table 1. These findings indicate that the scales are consistent and stable across a diverse range of sites, subject populations, and clinical or human service areas.

Moderately high item-total correlations seen in Table 1 are consistent with the underlying single factor structure of the CSQ scales derived from factor analyses of the underlying data. These findings support the conclusion that the CSQ scales measure a global satisfaction construct.

Inter-item correlations reported in Table 1 are only moderate suggesting that beyond the global satisfaction factor there is additional variance due to error of measurement and/or differential responses to item content detected by respondents. Since an important goal of the research program is

the development of a multifactorial scale, the existence of unaccounted variance was a stimulus to further research leading to the SSS scales.

In addition, we have found that the CSQ scales almost always produce negatively skewed rating distributions when total raw scores or mean of item means are analyzed. These results indicate generally high satisfaction levels across sites and service types including mental health services and primary care services. These findings stimulated our interest in continuing to develop multifactorial satisfaction measures that could yield more normal score distributions within factorial components. The SSS scales are representative of our efforts to achieve this goal.

Research Leading to the SSS-30 Scale

Methodological Problems and Steps to Their Solution

Following the publication of Patient satisfaction in health and mental health services by Attkisson and Pascoe in 1983, the UCSF research group embarked on scale development research aimed at addressing scale limitations and challenges identified in earlier studies.

During the initial research phase, various methodological problems emerged that could not easily be solved with the CSQ series of scales. To solve these problems, the CSQ scales were used as comparison measures in experimental designs to assess methodological factors in patient and consumer satisfaction. Various alternative methods were compared including (a) ranking methodologies (Pascoe & Attkisson, 1983; Attkisson et al., 1983) and (b) indirect and direct approaches to assessing satisfaction (Pascoe et al., 1983). In addition, during the second phase, we attempted to write more refined and specific item pools and combined item pool enhancement with adoption of the Andrews and Withey (1976) scaling approach used in the successful development of quality of life measures (Attkisson, Greenfield, & Spradling, 1986; Pascoe, 1983, 1984). This work culminated in the SSS-30 (Greenfield & Attkisson, 1989).

The Service Satisfaction Scale-30 was designed to assess multiple factors of service provision with a special focus on those conceptual factors identified as most salient by consumers of health and human services. Initial item content included items assessing a number of important dimensions in the Ware et al. taxonomy of satisfaction (Ware, Snyder, Wright, & Davies, 1983); particularly: interpersonal manner, technical quality, efficacy/outcome, accessibility/convenience, finances, physical environment, and availability. Item writing was also informed by the earlier empirical studies at UCSF (Attkisson & Pascoe, 1983) and various reviews (Lebow, 1983; Pascoe, 1983). While focused on specific features of a service, original SSS items were written "generically" so as to make their content apply meaningfully across a broad range of health, mental health and chemical dependency services (Greenfield & Attkisson, 1989). Italian language versions of the SSS scales have also been developed in Italy (Ruggeri, Dall'Agnola, Greenfield, & Bisoffi, 1995; Ruggeri & Greenfield, 1995).

The SSS research program addressed several basic problems noted with the CSQ scales: sensitivity and scaling, general versus specific factors, and reliability. Each of these areas is discussed in more detail below.

Sensitivity and Scaling

The CSQ scales (as is also characteristic of many other service satisfaction measures) tend to yield negatively skewed distributions — given the tendency of recipients to report high levels of service satisfaction. Approximately 10% of respondents are generally found to be dissatisfied; however, it is difficult to distinguish degrees of satisfaction among the majority of respondents whose ratings accumulate at the most satisfied levels and cannot easily be distinguished from one another. To "normalize" the distribution of scores, alternative rating procedures have been introduced. Instead of the four-level rating scale used in the CSQ, the SSS instrument employs five- (and in one study seven-) level anchored item response scales that were originally used in quality of life studies (Andrews & Withey, 1976; Lehman, 1988). Work with the SSS series demonstrated that use of the more extreme "Delighted" and "Terrible" anchors reduced the ceiling effect and negative skew typical of CSQ results. This was true even when using the five-level rating scale instead of the seven-level rating (Andrews & Withey, 1976). Experience with consumers and staff confirms that the SSS scale's item content has good face validity.

General versus Specific Factors

Despite item content representing logical or conceptual domains, the earlier CSQ work consistently yielded one replicable general satisfaction factor. We have investigated changes in the questionnaire design that would allow us to assess several empirical factors corresponding to theoretical domains of the service satisfaction construct. The primary innovative value of the SSS-30, however, is its factor-based subscale scores. The SSS-30 uses items that are more specific than those included in the CSQ item sets. In combination with the changed scaling, the introduction of more differentiated item content has yielded a strong foundation for a multi-factorial instrument. With the SSS-30 we have achieved the capacity to discriminate among service-related components and to measure differential levels of satisfaction with the various components. Factor analyses of the SSS-30 ratings of consumers within primary care and mental health outpatient services yielded two stable and replicated subscales:

1. Practitioner Manner and Skill (9 items; average Cronbach's alpha across studies = .88)
2. Perceived Outcome (Efficacy) (8 items; average Cronbach's alpha across studies = .83)

Two additional though less stable dimensions were also found. However, these latter factors were not consistently identified across settings included in the scale development study:

3. Office Procedures (5 items; average Cronbach's alpha across studies = .74)
4. Accessibility (4 items; average Cronbach's alpha across studies = .67).

We place most confidence in the first two repeatedly confirmed and widely relevant subscales. The less stable factors nevertheless may also be useful in specific service evaluations.

For subscales to have validity and interpretability (i.e., similar meaning) across settings, a basic requirement is that the factors on which they are based should have a high degree of replicability. Greenfield and Attkisson (1989) and Greenfield (1989, 1994) provided evidence of factorial invariance across a range of health and mental health service settings. Across several distinctly different types of service, the major factors of Practitioner Manner and Skill satisfaction and Perceived Outcome satisfaction are well confirmed. Factors involving constructs such as satisfaction with Office Procedures and Access to needed services appear less stable across research study sites and their constituent items correlate in more setting-specific ways.

The SSS-30 contains a broad array of specific items pertaining to the consumer experience of service access, acceptability, provision, and outcome. Available data on psychometric performance of the SSS-30 include norms from a general population primary-care medical outpatient service, a student mental health service (Attkisson & Greenfield, 1994; Attkisson et al., 1986; Greenfield & Attkisson, 1989), an employee assistance program (see Greenfield & Attkisson, 1989) and repeat DUI offenders in a mandatory 15-session treatment program (Greenfield, 1989, 1994). Table 2 resents a summary of currently available information about the psychometric performance and factor structure of the SSS-30.

Psychometric Properties of the Client Satisfaction Questionnaire Scales (CSQ-8; CSQ-3/4) as Reported in Various Studies

Published Studies	Roberts et al. (1983a)	Roberts et al. (1984)	Greenfield (1989)(c)	Greenfield, Beigel & Torre (1995)
CSQ Scale Version	CSQ-8	CSQ-8(S)	CSQ-8	CSQ-8
Sample Size	n = 42	n = 101	n = 1,464	n=506
Sample Ethnicity	Mexican-American	Hispanic	Diverse	Adult & Child
Health Domain	Mental Health	Family Services	Drinking Driver Rx	Mental Health
Total score: (Average)	26.35	27.04	27.53	27.80
(Standard Deviation)	4.28	4.30	3.60	3.57
Mean of Item means	3.30	3.38	3.44	3.48
Mean of Item variances	0.51	0.49	0.40	0.41
Coefficient alpha	0.90	0.90	0.86	0.85
Median Item-total (b) *r*	(a)	0.69	0.62	0.60
Minimum Item-total *r*	0.44	0.56	0.48	0.47
Maximum Item-total *r*	0.77	0.78	0.66	0.67
Mean Inter-Item *r*	0.44	0.53	0.44	0.42
Minimum Inter-Item *r*	0.13	0.32	0.30	0.25
Maximum Inter-Item *r*	0.78	0.72	0.57	0.59

(a)Data not available (b)Item-total correlations are corrected for the presence of the Item being evaluated. (c)Reported in Attkisson and Greenfield (1994,p. 407). (d)Data are abstracted from the references cited in this table.

The validity of the CSQ-8 as a general satisfaction measure is more well established than for the SSS-30 scale. The correlation between the SSS-30 total score (as a composite satisfaction indicator) and the CSQ-8 was examined in a drinking driving treatment program. The SSS-30 total raw score correlated .70 with the CSQ-8 total raw score lending empirical support for the construct validity of the composite SSS-30 measure (Greenfield, 1989, 1994). In the drinking driving treatment study, the mean CSQ-8 score for treatment recipients was 27.21 (SD = 4.03) compared to the CSQ norm-group mean of 27.09 [SD = 4.01] (Nguyen et al., 1983).

Reliability

The SSS-30 total score can serve as a composite satisfaction measure with high internal consistency: Cronbach's alpha values have ranged from .93 to .96 (Greenfield & Attkisson, 1989). In addition several factor-based subscales have been identified in a series of studies. Table 2 provides psychometric properties of the Practitioner Manner and Skill satisfaction and Perceived Outcome satisfaction component subscales of the SSS-30 for four norm groups, showing that the two main subscales have good internal reliability. Cronbach alphas ranged from .83 to .93 (average .88) for the 9-item Practitioner Manner and Skill subscale, and .80 to .90 (average .83) for the 8-item Perceived

Outcome subscale. In addition, in none of the studies did analyses indicate that the removal of any item would increase reliability, consistent with their development by factor analyses and the high congruence of these two factors across settings. Internal reliability coefficients for the two smaller subscales are lower, ranging from .69 to .83 (average .74) for the 5-item Office Procedures satisfaction subscale, and .60 to .75 (average .67) for the 4-item Access satisfaction subscale.

Readability of the CSQ and SSS Scales

Readability refers to the degree of difficulty for a reader to comprehend a text document. Readability formulas are tools used to predict the comprehension difficulty of text and how hard material will usually be in relation to the reading ability of prospective readers (Chall & Dale, 1995, p.45). Classic readability formulas are based on theory and research in language development and reading comprehension (Chall & Dale, 1995, p. 93). Reading development research has demonstrated that reading comprehension is best predicted by vocabulary knowledge and that word difficulty is highly related to word length (Chall & Dale, 1995, p. 117-118). An optimal match between text and reader is achieved when a reader is able to read and comprehend a given text independently. Reading formulas were developed to provide greater accuracy and efficiency in evaluating text difficulty than that derived from expert judgment (Chall & Dale, 1995, p.79). Text comprehensibility is influenced by factors aside from the innate difficulty of the material. These factors include how interesting the text is for a particular reader as well as the reader's motivation and familiarity with the subject matter.

The popularity of readability formulas lies in their capacity to match reading materials to the reading abilities of individuals (Azkaluk & Samuels, 1988, p.18). These formulas estimate text difficulty on the basis of factors that have the highest prediction of difficulty (Chall & Dale, 1995, p. 5). Classic readability formulas are based on the two most potent factors for measuring text difficulty: word difficulty (semantic qualities), and sentence difficulty (syntactic qualities). In classic formulas the strongest predictor of overall text difficulty is word difficulty as measured by word frequency, familiarity, or word length. The second predictor used in classic formulas, sentence length, correlates well with syntactic complexity. These two factors correlate highly with reading comprehension determined by cloze procedure[1] comprehension scores (Chall & Dale, 1995, p. 6). Readability formulas work on average word difficulty and sentence length. They are based on the idea that for text to be easier to read the average sentence and word will be shorter ((some sentences and words can be long, and some short, but on average will be shorter (Fry, 1986, p.3). This does not mean though, that all short words are common and easy, or that all long words are uncommon and difficult. Nevertheless, research supports the assertion that high frequency words are shorter and easier to understand (Coleman, 1971, cited in Fry, 1986, p. 3). In summary, classic "readability formulas... simply state that in general (and) on the average, two inputs of sentence length and word difficulty accurately predict how easily a given passage will be understood by the average reader" (Fry, 1986, p. 7). Readability formulas can also give an estimate of listening difficulty for subjects who do not have adequate literacy skills to read a selected text. Listening comprehension is easier than reading comprehension for text difficulty up to the eighth grade level; about equal difficulty up to the twelfth grade level, and harder to understand for higher grade levels.

Critics of classic readability formulas have faulted them for not reflecting other important features of text difficulty such as the organization of text, difficulty of ideas expressed, and for ignoring the interaction of text and reader characteristics (Chall & Dale, 1986, Zakaluk & Samuels, 1988). These critics have developed new methods based on cognitive psychological theory. However, these more sophisticated measures correlate well with scores obtained through classic readability formulas. Available formulas also are not yet in forms that can be easily used to evaluate text. Another common criticism of reading formulas is that they have been used to rewrite and 'dumb down' text (Fry, 1986, p.2). Defenders of reading formulas respond that the formulas were never intended to be writing formulas and should not be blamed when misused: "Readability formulas are not writeability formulas. Formulas are not and never were intended to be writers' guides" (Fry, 1986, p.2). While reading formulas should not be used to write text to achieve a particular readability score, readability principles can be used to produce written materials for a target audience (Chall & Dale, 1995, p. 49). No readability formula, however, is a complete and full measure of text difficulty (Chall & Dale, 1995, p. 6). Formulas only measure a limited number of the many characteristics that make text easy

or hard to read and understand. An awareness of these limitations will lead to more effective use of readability measures.

During the development of the CSQ and SSS scales no formal attention was given to the issue of reading difficulty. The scales were written for use by consumers of health and human services in general with the intent that they should be understandable by the "average" client. In the case of the SSS, in a number of instances, items that might include a difficult word like “procedures” in item 5. “Office procedures” were written to include a parenthetic example or examples, in this instance “(scheduling, forms, tests, etc.)”. Thus, someone reading the item was given further clues about its content meaning.

Reading difficulty of the English versions of the CSQ and SSS was calculated using the Flesch-Kincaid and Flesch readability formulas included in the Microsoft Word© word processing software. These formulas are widely used to evaluate the ability of readers to comprehend written materials (Clariana, 1993; Cramer, 1978). The Flesch-Kincaid formula reports the educational grade level necessary to understand the document and is based on the average number of syllables per word and the average number of words per sentence. A score of 6.0 indicates that an average sixth grader should understand the material. Standard writing is equivalent to an average seventh to eighth grade level (Microsoft, 1993-94, p.101). The lower the grade level, the easier the text is to read. The Flesch reading ease scale is an index based on the average number of syllables per word and the average number of words per sentences. A score is produced from 0-100 with higher scores indicating greater ease of reading. Standard writing has an average score of 60 to 70. Higher Flesch scores indicate an easier reading level.

The overall difficulty scores for the CSQ-8 are 69.4 for the Flesch reading ease index and 4.7 grade level for the Flesch-Kincaid formula. The summary scores for the CSQ-18A and CSQ-18B are 58.0 and 58.6 for the Flesch formula, and 6.2 for the Flesch-Kincaid grade level. The reading scores for the SSS-30 are 65.7 for the Flesch reading ease index and 6.4 grade level for the Flesch-Kincaid formula. Clients with approximately a sixth grade reading level should therefore be able to complete any of the instruments with relative ease.

TABLE 3: READING DIFFICULTY OF THE SCALES

SCALE	Flesch Formula reading ease level. Standard Reading = 60-70 score (1)	Kincaid-Flesch Formula grade level. Standard reading = 7.0-8.0 grade level (2)
All-item total for CSQ-8	69.4	4.7
All-item total for CSQ-18A	58.0	6.2
All-item total for CSQ-18B	58.6	6.2
All-item total for SSS-30	65.7	6.4

(1) Higher score indicates easier level

(2) Lower score indicates easier level

Relationship of Demographic Variables and SES to CSQ Scores

Demographic variables and socio-economic status (SES) do not explain a large proportion of the variance in patient satisfaction ratings among clients completing the scales in English in the U.S. (Attkisson & Pascoe, 1983; Nguyen et al., 1983). Two variables having modest explanatory power are gender and age for which somewhat stronger relationships have been reported (Pascoe, 1983). For example, women and respondents at the age extremes have reported somewhat higher consumer satisfaction levels (Pascoe, 1983). Overall, however, demographic and SES variables do not explain service satisfaction variance. These findings indicate that satisfaction with services is most likely an independent construct and that service satisfaction is not a surrogate for demographic or socio-economic status. In any given study, nevertheless, it remains essential to assess and control for the degree to which satisfaction data may be confounded by the characteristics of consumers, their economic status, or their external life circumstances.

Relationship of Life Satisfaction to Service Satisfaction of Consumers

Consumer satisfaction with a specific health service has not been found to co-vary with self-ratings of life satisfaction or with general attitudes about the "health care system" (Roberts, Pascoe, & Attkisson, 1983b). This indicates that service satisfaction ratings may be independent of life satisfaction ratings and from general attitudes about the health system. For example, studies using the CSQ indicate that this measure of service satisfaction does not serve as an indirect proxy for life satisfaction, or for satisfaction with health care in general, or for attitudes about health care providers. Nevertheless, in all studies of consumer satisfaction it is advisable to include supplementary measures of: (a) life satisfaction (general and specific factors), (b) self-perception of health status, and (c) general attitudes about the health care system (or human services).

USE OF THE CSQ AND SSS SCALES IN CROSS-CULTURAL AND NON-ENGLISH SPEAKING CONTEXTS

The concept of client satisfaction in other cultural and language contexts

The CSQ and SSS scales were developed as multi-purpose instruments for use across the spectrum of health and human services. It is also important to evaluate client satisfaction among non-English speaking and bilingual ethnic minority clientele.

Efforts to translate the CSQ and SSS for use in other cultural and linguistic contexts rest on the assumption that the concept of satisfaction regarding the receipt of health and human services has salience in these other contexts or countries. However, service recipients in other cultural and national contexts may not understand the concept that services could or should be different or better, or that they, as consumers could provide constructive input into the change process. A central consideration in the use of established scales in other languages is the need to separately address the issues of adequacy of the instruments for measuring the phenomenon of interest, adequacy of the translation, and adequacy of administration of the instrument. This section presents a discussion of the issues of translation and administration.

Use of established psychological measures in other language and cultural settings

The advantages of using the CSQ and SSS scales in other cultural and language settings versus independent development of unique instruments for each ethnic and culture group, lie in the well-established psychometric properties of the scales. However, the psychometric adequacy must be freshly confirmed for each new translation. Development of unique instruments for non-English language groups, and non-U.S. cultural contexts would require the same rigorous process of establishing basic psychometric adequacy. For cross-cultural use of a pre-existing instrument, functional equivalence (i.e., measures the same attribute in different groups) and score equivalence are important concerns (i.e., subjects from different cultural groups who receive the same scores as the referent group have the same amount of the attribute being measured) (Poortinga, 1975, cited in Davidson & Thomson, 1980, p. 32). Unfortunately, achieving score equivalence is extremely difficult due to a host of factors, such as lack of experience with test materials and test situations, lack of

understanding of test instructions, and variation in meaning associated with test items. Comparison of mean test score differences between cultural groups can therefore be problematic.

Cultural variation in client satisfaction

In evaluating satisfaction in ethnic minority, non-U.S., or non-English speaking contexts it is important to keep in mind factors that are the most important qualities of service to clients. "Different sociocultural world views can affect the way health-related experiences and information may be understood, utilized, and evaluated... cultural groups vary in what they consider to be important and desirable qualities..." (Ellmer & Olbrisch, 1983, p. 275). While certain generalizations can be made about particular ethnic and language groups, a "recipe" approach is not recommended for dealing with an individual from any group. Individuals will vary considerably in respect to such characteristics as concepts of satisfaction, language preferences (e.g., listening, speaking, reading, writing), acculturation, and familiarity and comfort with questionnaires and other evaluation scales. Cultural generalizations should not promote treating individuals in a stereotypical manner, but be used to sensitize staff to client characteristics that may influence their expectations and experiences with health and human services.

Research on ethnic minority groups in the U.S. suggests some general characteristics which can influence client expectations and experiences with health services. Among Latino-ethnicity clients the concept of personalismo is important. Personalismo refers to a quality of personal relationship, traditionally the tendency to distrust official institutions and preferentially rely on personal ties (Foster, 1961). In a health care setting, personalismo can influence satisfaction through a preference for individual personal contact and attention. Developing rapport and listening to the patient are of paramount concern (Ellmer & Olbrish, 1983). Without adequate explanation regarding the intent of the scales, the client's answers may reflect his or her feelings about the relationship with the provider rather than satisfaction on a broader basis.

The concept of face is often salient for Asian-ethnicity clients. Face involves issues of respect, both in showing respect towards professionals, and expecting respect in return. Any interaction that can result in a loss of respect or self-respect constitutes a loss of face. Satisfaction may be strongly influenced by expectations and experiences regarding respect in services. A client may also be reluctant to be candid regarding satisfaction to avoid causing loss of face. An inflated opinion might be offered to save or increase face for a clinician or center that is respected.

In the Italian translation of the SSS-30, item ten which asks about personal manner of the psychiatrist or psychologist was changed in the Italian to the manners of the psychiatrist and psychologist (M. Ruggeri, personal communication, 1994). In the Italian context the manners of a clinician are very important to a client in assessing satisfaction, and may also be viewed as a crucial component of the broader construct manner, or ‘mode of approach.’

Recent immigrants and refugee populations may present challenges for scale administration. These groups may be unfamiliar or even uncomfortable with completing questionnaires. Information collection may be threatening to refugees from countries with political persecution where all information can be used against a person and where ‘confidentiality’ is not a bureaucratic value. Refugees may be very protective of their privacy, suspicious about the actual intent of the questionnaires, or fearful about how information will be used. At the same time, most refugees and immigrants have experience with the need to complete forms as a part of coming to the U.S. They will tend to be very careful about what they write and often attempt to answer what they think is wanted or what they believe is safest. It may be prudent with such client groups to check for "perfect responses" (i.e., gives the highest score for all items) which might suggest that the client is not answering honestly and to eliminate such responses from the overall calculation of client satisfaction. The alternating direction of the item scales in the SSS-30 was designed in part to allow removal of another stereotypic form of responding ¾ where the respondent simply checks all the rightmost or leftmost categories without reading the questions.

The difficulties immigrants have with scale completion were demonstrated during pilot testing of the CSQ and other scales translated into Korean and Vietnamese for Los Angeles county (J. Abe-Kim, personal communication, October 10, 1996). The translator for the project found that subjects needed someone to guide them and help them complete the questionnaires. There was a general lack of familiarity with paperwork and subjects commonly found the questionnaires overwhelming. This

occurred most strongly for subjects with less than a high school education, for women, and for individuals over 40 years of age. Among Vietnamese immigrants who had past traumatic experiences such as having been in jail in Vietnam, it was very difficult to concentrate on the questionnaire and a great deal of effort was required. The subjects participating in the pilot test knew and trusted the translator, but it appeared likely that there would be additional trust concerns in situations where clients did not know staff well. Generalizing from this instance, special attention to administration and needed accommodations may need to be considered for all special populations.

What is a scientific translation?

The goal of all translations should be "not merely transposing from one language to another... (but) throwing a semantic bridge between two different cultures, two different 'thought-worlds'" (Namy, 1977, p. 25). Research on "gold standard" translations (Berry, Trimble, & Omedo, 1986; Bravo, Woodbury-Fariña, Canino, & Rubio-Stipec, 1993; Brislin, 1986; Brislin, Lonner, & Thorndike, 1973; Hui & Triandis, 1985) describe a number of techniques that can be employed to optimize a translation. These techniques include utilizing "translatable English" when writing the original instrument" (Brislin et al., 1973, p. 33); use of professional translators; employing a combination of translation methods (e.g., decentering in which the English version is open to revision; multiple forward and back-translations by bilingual translators); and, use of a bilingual review committee to evaluate the adequacy of a translation. It is also helpful to utilize translators who are well acculturated in the original and target cultures, as well as being familiar with the content area of the instrument (e.g., bilingual psychologists for psychological instruments). Bilingual speakers can vary in their language competence because of a host of factors (where language was learned, e.g., from immigrant parents vs. in origin country; country/region of origin; time since immigration; acculturation; education; and, class). It may therefore be useful to develop a method for determining the competence of nonprofessional bilingual translators in reading and writing the target language (e.g., a person can acquire bilingual oral language ability from parents, but may not have been formally educated to read and write the target language). A person can, however, be fully competent in written forms of a language without being a bilingual speaker (Thiery, 1977, p. 15). Translated instruments should always be pilot tested with monolingual speakers who are preferably representative of the target population. One should be aware that regional dialects or differences in expressions among immigrant groups from distinctive linguistic traditions may need to be taken account of in seeking a broadly useful translated instrument.

A creative technique was employed during the development of the Hispanic Health and Nutrition Examination Survey (HHANES) to minimize the problems encountered when the original English version is not subject to revision and when the target populations may have significant ethnic and regional variations in language (Maurer, 1985; Treviño, 1985). Certain words and terms had distinct meanings to the different Spanish language groups (i.e., Mexican-American, Puerto Rican, and Cuban-American). In such cases, the translation included a descriptive phrase that might not be the preferred wording for a particular group, but would be easily understood by all groups. For example, the phrase "la comida de mediodía" (midday meal) was used to translate "lunch". A second problem involved the language groups using different words for the same concept. In this case, the questionnaire included alternate word selection for the item, for example "puro/tabacos/cigarro" to translate "cigar". Such problems may not be confined to non-English instruments, and may be useful even in English. For example, as mentioned earlier, a similar technique was used with the English-language SSS which incorporated the use of parentheses with expansions, definitions or examples to facilitate understanding. Thus, without changing item meaning it might be possible to provide culturally relevant parenthetic content fitting the specific service needs in another context. In both examples, however, the alternate-word approach might require well-trained interviewers who can select the most appropriate word, depending on the skill levels of the target population.

Translation and acculturation are very much interrelated for non-English speaking immigrant populations in the U.S. The "version" of a target language to be used should be informed by a deep appreciation of how acculturation has impacted language use. For example, during pilot testing of a Tagalog translation of the CSQ and other instruments the translator discovered that "pure" Tagalog sounded artificial or too proper to participants (J. Abe-Kim, personal communication, October 10, 1996). In common usage, Tagalog incorporates many English words, terms and expressions, even in

the Philippines because of U.S. influence, especially in the educational system. The translator reported that among individuals with low socioeconomic (SES) status it is common to use a "mixed" Tagalog, but for individuals with medium or high SES the amount of English used increases substantially. A natural sounding Tagalog translation thus might incorporate some English. At the same time, the translator also found important conceptual differences between English and Tagalog. For example, the term "pain" in English can be applied to many different kinds of pain, whereas in Tagalog it is necessary to specify emotional or physical pain.

Translations of the CSQ and SSS

The CSQ and SSS scales have been used with various sub-populations and language groups in the United States and abroad. To date the CSQ-8 scales have been translated into French, Spanish, Dutch, Chinese, Tagalog, Vietnamese, Korean, and Cambodian. A modified version of the SSS has been translated into Italian. A shortened Spanish version has been used in Puerto Rico. Additional Spanish translations of the SSS are currently in process by researchers in Barcelona, Spain, a project in Phoenix, Arizona, and a managed care project in Florida. The process of translation has varied considerably with regard to methodological rigor used in developing the translation.

A common feature of translation efforts for the CSQ and SSS is that minimal financial resources are available. This is undoubtedly true for translations of many other well-established psychological scales. The almost exclusive attention to the development of English-language instruments, and the near absence of instruments independently developed in other languages in the U.S. has been lamented by activists in the cultural competency movement (R. Guerrero, personal communication, July 16, 1996). We strongly encourage the devotion of more research attention and resources to the development of satisfaction scales for specific language and cultural groups.

The developers of the CSQ and SSS scales focused on covering the relevant domains of client and service satisfaction and achieving optimal psychometric properties. They did not write the scales with their potential use in other language and cultural contexts uppermost in mind. Therefore, there was no formal effort to use translatable English which can facilitate the translation process. The scales had been refined and their psychometric properties well-established before interest developed in translating the instruments into other languages. Therefore, it was not possible for the original English wording to be modified to facilitate translation, as necessary with the "decentering" technique (Brislin, 1986; Brislin et al., 1973; Hui & Triandis, 1985).

To date, the developers of the scales have actively collaborated on two translations. Roberts coordinated a Spanish translation of the CSQ-8 (Roberts & Attkisson, 1983; Roberts, Attkisson, & Mendias, 1984; Roberts, Attkisson, & Stegner, 1983). Greenfield collaborated on the translation and adaptation of the SSS into Italian and Spanish. Aside from these cases, the developers of the CSQ and SSS scales did not participate in any systematic way with any of the other translations of the scales on such matters as clarifying the conceptual intent of items. The developers of the instruments therefore cannot attest to the semantic, content, technical, criterion, or conceptual equivalence of the other translations (Bravo et al., 1993).

Translations of the CSQ-8 into Spanish

Roberts and colleagues developed a Spanish version of the CSQ-8 with funding from the National Institute of Mental Health (Roberts & Attkisson, 1983; Roberts et al., 1984; Roberts, Attkisson, & Stegner, 1983). Three independent bilingual Spanish-English translators representing the three major Spanish-language groups in the U.S. (i.e., Mexican-American, Cuban, and Puerto Rican) developed translations that were subjected to a blinded back-translation by a second bilingual translator of the same linguistic group. These translations were subsequently evaluated by a committee made up of the translators and mental health professionals. A definitive Spanish version was agreed upon, pretested, and revised slightly, resulting in a final version. Further evidence of equivalence with the English version was demonstrated by comparing the results of bilingual English-Spanish speaking clients who were randomly assigned to complete the CSQ in English or Spanish.

In 1995, C. Attkisson undertook a revision of the Roberts et al. (1984) Spanish version. In this translation process, five Spanish speakers reviewed the Robert's translation to enhance the translation for use with the widest range of Spanish-speaking groups. Both versions are now available for use.

Translations of the CSQ-18B into French

Sabourin and colleagues developed a French translation of the CSQ-18 Form B (which includes all items from the CSQ-8) (Sabourin & Gendreau, 1988). Sabourin describes his translation process as that of a "committee approach" (Sabourin & Gendreau, p. 330). Independent bilingual (French-English) translators produced French versions which were then reviewed by different bilingual evaluators. A consensus was reached on the optimal wording in French to best capture the original English concepts.

Translations of the CSQ-8 into Dutch

The Dutch translation process is described by De Brey (1983). The initial Dutch version was produced for a mental health center in Holland by two bilingual (Dutch-English) translators and reviewed by a group of university faculty and mental health professionals. This translation was then submitted for further evaluation by a committee convened by the center's administration. The Dutch translation modified the English CSQ further by adding two additional items that did not appear in the original version, i.e., length of therapy sessions and decision to terminate therapy. (Interests of the Dutch investigators).

Translations of the CSQ-8 into Chinese, Tagalog, Vietnamese, Korean, and Cambodian

During the early 1980s, the staff of the San Francisco Department of Mental Health undertook translations of the CSQ-8 into Chinese, Tagalog, and Vietnamese as part of an extensive community survey. These translations efforts were part of an overall attempt to improve services for minority client groups in San Francisco.

More recently, the Los Angeles County Department of Mental Health has commissioned translations of the CSQ-8 and other instruments[1] into several Asian languages. Under the direction of Dr. Stanley Sue and Dr. Jennifer Abe-Kim, the National Research Center on Asian American Mental Health (NRCAAMH) agreed to facilitate the process of translating the instruments into Chinese, Korean, Vietnamese, Tagalog, and Cambodian. The committee was charged with developing a translation strategy. The resulting process included: (1) a bilingual speaker of each target language and English independently developed a translation of the instruments;[1] (2) the initial translation was evaluated by two independent bilingual individuals who reviewed the target language version (with the English language version available as a guide) and made suggestions for changes;[1] (3) the translated instruments were then pretested with five monolingual subjects who were generally representative of the potential client population and verbal feedback was solicited from the pretest subjects regarding any aspects of the questionnaires that were problematic; and, (4) the suggestions of the reviewers and pretest subjects were used to revise the translated questionnaires (e.g., there were some terms and idiomatic expressions in the questionnaires that did not have direct equivalents in the target language; in such cases a conceptually similar term was utilized). The final versions produced by NRCAAMH have been submitted to the Los Angeles Department of Mental Health which is independently evaluating and field testing the translations.

Psychometric characteristics of the translated versions of the CSQ

Translators of the Spanish, French, and Dutch versions of the CSQ report similar operating characteristics and psychometric properties as the original English instrument. (De Brey, 1983; Roberts et al., 1984; Sabourin & Gendreau, 1988). The French-language version of the CSQ-18 was reported to score lower on homogeneity than the CSQ-8 (Sabourin & Gendreau, 1988, p. 333). This finding for the French CSQ-8 and CSQ-18B is consistent with findings for the English versions (Sabourin & Gendreau). They conclude by recommending the use of the French CSQ-8 rather than the CSQ-18B for evaluation of patient satisfaction.

Roberts et al. (1984) have established that the psychometric equivalence of the Spanish CSQ-8 (CSQ-8S) by administering the scales to bilingual Latino clients who were judged by clinicians to be adequately bilingual to complete the scale in English or Spanish. Clients were randomly assigned to complete the CSQ-8S in either English or Spanish. A cross-over test of reliability was also conducted in which Latino clients were divided into three groups: those who took the CSQ in Spanish initially and at follow-up, those who first completed the questionnaire in English and in Spanish at follow-up, and those completing the scale in Spanish initially and later in English. This procedure demonstrated

that the CSQ has similar operating characteristics when administered to Anglos or Latinos in English or Spanish.

Translation of the SSS-30 into Italian

Ruggeri and colleagues have modified and added to the SSS-30 for use in the Italian context. Additional items come from alternate SSS forms, such as the Family form (Greenfield) & Attkisson, 1989b) [see Maruish refs] a 38-item pilot version of the SSS-30, and other sources. The resulting instrument, the 82-item Verona Satisfaction Scale (VSSS-82) includes 29 of the original 30 SSS-30 English-language items which were translated or adapted (Ruggeri & Greenfield, 1995).[1] The retained and adapted English items were translated using a process of forward and back translation with additional "target checks" (N. Sartorius, personal communication, 1996). The preliminary Italian version of the scale was translated by Ruggeri who is bilingual in Italian and English. This translation was evaluated by a committee of five mental health professionals who suggested some modifications.[1] A pilot study was then conducted with five Italian patients. Problems with wording were identified and some wording changes were made to improve comprehension. This modified version was independently back translated by a U.S. student who spoke Italian fluently and a bilingual Italian psychiatrist. The back translation was evaluated by two monolingual English speakers: a British psychiatrist and T. Greenfield, the principal developer of the SSS-30. Attention was focused on achieving conceptual and psychometric equivalence between the Italian and English versions. Interestingly, some corrections suggested by the British evaluator misrepresented the U.S. English intent of the items. This suggests that use of English language scales by English speakers in other national contexts may be problematic, and may need to undergo a process of validating conceptual equivalence.

Psychometric properties of the VSSS-82

Psychometric properties of the VSSS-82 were evaluated by Ruggeri and colleagues (Ruggeri & Dall'Agnola, 1993; Ruggeri et al., 1995; Ruggeri & Greenfield, 1995). A validation study with 75 patients and family members was conducted to establish content and criterion validity. Test-retest reliability was evaluated with a subset of 25 subjects. The VSSS was found to measure patient satisfaction in a "sensitive, valid and reliable way" (Ruggeri & Dall'Agnola, 1993, p. 521). Factorial equivalence of the 29 items common to the SSS-30 and the VSSS-82 were investigated by Ruggeri & Greenfield (1995) finding some comparability of the two main factors, but especially of Perceived Outcome/Efficiency. This analysis also examined demographic and other service variable correlates of the satisfaction subscales finding outcome satisfaction inversely related to a number of service utilization variables such as number of outpatient contacts, days of hospitalization and number of drop-in contacts.

The WHO collaborative project

The World Health Organization (WHO) is currently directing a collaborative research study to translate a fifty-five item version of the Verona Satisfaction Scales into several European languages including Danish, German, and Spanish. These translations are not yet being disseminated for use.

Relationship of Demographic Variables and SES to CSQ Scores in other cultural and language contexts

As discussed above, demographic attributes are not well correlated to CSQ scores among English-speaking clientele. In contrast, a relationship between demographic factors and client satisfaction has been found by Ruggeri & Greenfield (1995) with SSS-30 items included in the longer Italian SSS-82 and the Roberts et al. (1984) Spanish CSQ-8. In the Ruggeri study, client satisfaction was found to be influenced by age and educational level. Roberts et al. (1984) compared the responses of three groups completing the CSQ: Anglo-English, Hispanic-English, and Hispanic-Spanish. A trend was identified in which Anglos were more satisfied and Hispanics completing the Spanish language CSQ were least satisfied. Among Hispanics, women completing the English CSQ were slightly more satisfied, more educated Latinos completing the CSQ in English or Spanish were less satisfied, and employed Latinos completing the Spanish CSQ were less satisfied.

Administration of the CSQ and SSS Scales in Other Cultural and Language Contexts

As discussed previously, administration procedures are of central consideration in obtaining valid results for any consumer satisfaction measure (Attkisson & Greenfield, 1994, p. 404). Response rates can vary significantly according to the administration techniques employed and low response rates can introduce a serious source of bias. Client response can be affected by the method of questionnaire administration (Lebow, 1983, Nebeker (1992) Ref. in Maruish dept. p. 215). Attkisson and colleagues report that oral administration of a questionnaire resulted in a mean score ten per cent higher than written administration (Attkisson et al., 1983). Administration by mail is not recommended as this technique usually results in unacceptable response rates even with follow-up (Attkisson & Greenfield, 1994, p. 405). Detailed planning for intensive follow up might offset these problems to some degree. However, phone administration has met with some success, for example, in one study of child case management services (Salk, Greenfield & Attkisson, 1997).

We anticipate several potential non-English and cross-cultural contexts for the use of the scales. These might include: (1) minority non-English speaking clients where few staff (e.g., the client's clinician) speak the client's language; (2) specialty clinics for minority non-English speaking clients where most or all clinicians and support staff speak the client's language; (3) clinics with multi-ethnic, non-English speaking clients using a variety of languages, where some staff speak the client's language, or are assisted by interpreters; and, (4) non-U.S. settings where the clients and staff speak the same non-English language. Each of these situations may call for different administration techniques in regards to who determines the language and literacy competence of the client and evaluates if the questionnaire can be self-administered or if the clients will need assistance, who explains the questionnaire to the client, and who administers the questionnaire or assists with the administration (e.g., reads the questionnaire to the client and fills out the answers). In planning for scale administration for non-English speaking and bilingual clients it is useful to identify the language skills of staff who can administer the scales in languages besides English. Training of staff should include methods for establishing client competence and preference for completing the scales (e.g., written/oral English; written/oral other language, and how to administer the scales to clients who are illiterate or to disabled to complete the scales independently. (as has been the case in some studies involving people with serious psychiatric disabilities (Greenfield & Stoneking, 1993).

During the validation of the Roberts CSQ-8 Spanish translation (Roberts et al., 1984), project staff instructed clinical and support staff at each participating center on procedures for administering the scales and data collection. Counselors were asked to explain the purpose of the questionnaire to their clients, obtain informed consent (English or Spanish), and request that their clients complete the scale at the service site. If a patient was unable to complete the questionnaire independently (e.g., of limited reading ability, physical disability) assistance was provided. Latino clients were asked to participate only if they were judged by their clinician to be adequately bilingual to answer the questionnaire in either English or Spanish. (Roberts et al., 1984, p. 387-388).

Ruggeri and colleagues used a similar rigorous administration procedure during the research phase of developing the VSSS-82 (Ruggeri & Dall'Agnola, 1993). Interviewers received two days of training in administration of the scale. The interviewers read the items to the client and family members because of the anticipated difficulty with self administration due to low literacy levels as well as possible severe mental disorder in the patient group.

EMERGENCE AND REFINEMENT OF THE SATISFACTION CONSTRUCT IN SERVICE OUTCOME ASSESSMENT

Satisfaction measurement has achieved the status of an important domain of assessment in health and human service outcome assessment. Recent reviews and compendiums of outcome measures for health, mental health, and human services emphasize the importance of gathering information on consumers' satisfaction with services received (e.g., Ciarlo, Brown, Edwards, Kiresuk, & Newman, 1986; Hargreaves & Shumway, 1989; Rosenblatt & Attkisson, 1993). The CSQ and SSS scales are direct measures of service satisfaction designed to be used within a wide range of client groups and service types. These scales have been used in mental health programs, with primary medical care patients, in several chemical dependency treatment programs, and other human service settings. The availability of comparative norms and published applications focusing on individuals

varied by degree of disturbance and a range of sociodemographic variables have reinforced the unusually broad suitability of these measures.

The initial focus of the UCSF research program was on clients in mental health care. Our work gradually expanded to the broader spectrum of patients in primary health care and other social services. Health and human service settings studied, to date, include public health center clinics (Attkisson & Zwick, 1982; Attkisson et al., 1983; Pascoe, 1984; Pascoe & Attkisson, 1983; Pascoe, Attkisson, & Roberts, 1983; Roberts et al., 1983) primary care health clinics and health maintenance organizations (Attkisson & Greenfield, 1994; Greenfield & Attkisson, 1989), employee assistance programs (see Attkisson & Greenfield, 1994), mandatory short term alcohol abuse treatment programs for drunk drivers (Greenfield, 1989, 1994), and residential alcoholism treatment programs (see citations in Attkisson & Greenfield, 1994). The SSS scales are also being used to evaluate community-based residential care and case management for the individuals with severe mental disorder (Greenfield & Stoneking, 1993) psycho-educational groups (Scheafer, 1992).

Major accomplishments by investigators in the UCSF service satisfaction research program include:

1. The initial contribution of the UCSF research program was to demonstrate the significance and utility of including consumer satisfaction measures in clinical and services research.

2. The various CSQ scales were widely reported by UCSF and other independent investigators as having very high levels of internal consistency and consumer acceptability. The scales have been adopted in evaluation studies and clinical research across the spectrum of health and human services.

3. Demographic variables and socio-economic status do not explain a large proportion of the variance in patient satisfaction ratings among most groups. This is true even for variables like gender and age where somewhat larger relationships have been reported. Women and respondents at the age extremes, however, have reported somewhat higher consumer satisfaction levels.

4. Consumer satisfaction with clinical services has not been found to be related to level of life satisfaction satisfaction or with attitudes about the "health care system" in general.

5. The CSQ and SSS scales, translated into other languages using culturally sensitive translation methods, perform equivalently across several national and cultural groups. The most extensive cross-cultural work has been done in Spanish with Latino populations.

6. The transfer of service satisfaction methodology from mental health to primary care and other settings:

a. The CSQ and SSS measures perform well in mental health, primary care, and other human service settings.

b. The measures are face valid and well accepted by staff, clients, and consumer advocates.

c. The measures have high utility to program planners, managers, consumers, advocates, and researchers.

d. Readiness for use of consumer satisfaction data seems attributable to the competitive market forces operating in health care systems today as well as to the consumer movement and demands for quality assurance.

7. Improved sensitivity and psychometric performance:

a. The CSQ and especially the multifactorial SSS measures include items on specific aspects of service provision while being relevant for use across many types of services and settings.

b. Improved item scales and anchors employed within the SSS scales result in less skewed item and subscale distributions that are suitable for multivariate and parametric analyses.

c. The item content of identified SSS factors and resultant factor-based subscales is readily interpretable and meaningful in light of prior research and theory.

d. Two factors within the SSS-30 scale have been replicated across a number of service types and settings. The first assesses Practitioner Manner and Skill of service providers, while the second assesses Perceived Outcome.

e. Several other factors within the SSS-30 scale display lower consistency and stability across settings. This appears to be because factors emerging within a specific service vary with its organizational characteristics. In one large health care system, for example, such factors found were: Accessibility, Treatment Continuity, Support Personnel, and Waiting Time.

The various phases of the UCSF research program have yielded important findings regarding use and interpretation of the CSQ and SSS measures. Scale development work has been primarily organized by empirical and practical considerations. The research has a strong conceptual framework and has produced measures that are face valid thereby aiding specificity of assessment by consumers (Pascoe, 1983). While our efforts have focused on improving the psychometric properties of the measures and to controlling for threats to reliability and validity, investigation of the satisfaction construct has been a principal research agenda. Though our studies have emphasized examination of antecedent factors affecting service satisfaction, we have also turned to methods of studying behavioral consequences of patient satisfaction, e.g., enrollment and disenrollment in health plans, compliance with medical regimens, prospective service use, and the relationship of early satisfaction to subsequent service use and outcome. The next generation of research studies will report on the use of the service satisfaction construct as an independent variable in relation to service use, cost, and outcome. The organizational structure of the system of care may also be strongly related to initial and long-term service satisfaction. Also, service satisfaction may well be an important determinant of consumer behavior within the care system (Hirschman, 1970). These important relationships will be an inviting focus in subsequent research.

In future research, investigators must also introduce improved control for variables that function as co-variates of satisfaction: demographic and personal characteristics, socio-economic status, and attitudes about health care. For example, an unpublished pilot study with the SSS in a multi clinic sample found that controling for variation in clinics' clientele was important (Greenfield, unpublished data). Age and gender effects are perhaps the most important candidates as covariates which may contribute variance to service satisfaction ratings, while life satisfaction and general attitudes toward the health care system have not been found in our research to be significantly related to direct measures of service satisfaction. Nevertheless, concurrent measurement of health care attitudes, life satisfaction ratings, and self-assessment of general health status can add significantly to overall precision and utility of a consumer satisfaction study. Within this framework, service satisfaction measures take an important place within the core array of outcome measures, health and functional indicators, and demographic classifications used in services research (Rosenblatt & Attkisson, 1993).

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CLIENT SATISFACTION QUESTIONNAIRE ©
CSQ-8

Please help us improve our program by answering some questions about the services you have received. We are interested in your honest opinions, whether they are positive or negative. *Please answer all of the questions.* We also welcome your comments and suggestions. Thank you very much, we really appreciate your help.

CIRCLE YOUR ANSWERS

1. How would you rate the quality of service you have received?

4	3	2	1
Excellent	*Good*	*Fair*	*Poor*

2. Did you get the kind of service you wanted?

1	2	3	4
No, definitely not	*No, not really*	*Yes, generally*	*Yes, definitely*

3. To what extent has our program met your needs?

4	3	2	1
Almost all of my needs have been met	*Most of my needs have been met*	*Only a few of my needs have been met*	*None of my needs have been met*

4. If a friend were in need of similar help, would you recommend our program to him or her?

1	2	3	4
No, definitely not	*No, I don't think so*	*Yes, I think so*	*Yes, definitely*

5. How satisfied are you with the amount of help you have received?

1	2	3	4
Quite dissatisfied	*Indifferent or mildly dissatisfied*	*Mostly satisfied*	*Very satisfied*

6. Have the services you received helped you to deal more effectively with your problems?

4	3	2	1
Yes, they helped a great deal	*Yes, they helped somewhat*	*No, they really didn't help*	*No, they seemed to make things worse*

7. In an overall, general sense, how satisfied are you with the service you have received?

4	3	2	1
Very satisfied	*Mostly satisfied*	*Indifferent or mildly dissatisfied*	*Quite dissatisfied*

8. If you were to seek help again, would you come back to our program?

1	2	3	4
No, definitely not	*No, I don't think so*	*Yes, I think so*	*Yes, definitely*

SAMPLE FORM
DO NOT USE

The *Client Satisfaction Questionnaire (CSQ)* was developed by Drs. Clifford Attkisson and Daniel Larsen in collaboration with Drs. William A. Hargreaves, Maurice LeVois, Tuan Nguyen, Robert E. Roberts and Bruce Stegner. Every effort has been made to publish information and research on the CSQ for widest possible dissemination.

http://saawww.ucsf.edu/csq

UCSF University of California, San Francisco

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CLIENT SATISFACTION QUESTIONNAIRE ©
CSQ-18B

Please help us improve our program by answering some questions about the services you have received. We are interested in your honest opinions, whether they are positive or negative. *Please answer all of the questions.* We also welcome your comments and suggestions. Thank you very much, we really appreciate your help.

CIRCLE YOUR ANSWERS

1. When you first came to our program, were you seen as promptly as you felt necessary?

4	3	2	1
Yes, very promptly	*Yes, promptly*	*No, there was some delay*	*No, it seemed to take forever*

2. In general, how satisfied are you with the comfort and attractiveness of our facility?

1	2	3	4
Quite dissatisfied	*Indifferent or mildly dissatisfied*	*Mostly satisfied*	*Very satisfied*

3. Did the characteristics of our building detract from the services you have received?

1	2	3	4
Yes, they detracted very much	*Yes, they detracted somewhat*	*No, they did not detract much*	*No, they did not detract at all*

4. How satisfied are you with the amount of help you have received?

1	2	3	4
Quite dissatisfied	*Indifferent or mildly dissatisfied*	*Mostly satisfied*	*Very satisfied*

5. Considering your particular needs, how appropriate are the services you have received?

4	3	2	1
Highly appropriate	*Generally appropriate*	*Generally inappropriate*	*Highly inappropriate*

6. Have the services you received helped you to deal more effectively with your problems?

4	3	2	1
Yes, they helped a great deal	*Yes, they helped somewhat*	*No, they really didn't help*	*No, they seemed to make things worse*

7. When you talked to the person with whom you have worked most closely, how closely did he or she listen to you?

1	2	3	4
Not at all closely	*Not too closely*	*Fairly closely*	*Very closely*

8. Did you get the kind of service you wanted?

1	2	3	4
No, definitely not	*No, not really*	*Yes, generally*	*Yes, definitely*

9. Are there other services you need, but have not received?

1	2	3	4
Yes, there definitely were	*Yes, I think there were*	*No, I don't think there were*	*No, there definitely were not*

SAMPLE FORM
DO NOT USE

10. How clearly did the person with whom you worked most closely understand your problem and how you felt about it?

4	3	2	1
Very clearly	*Clearly*	*Somewhat unclearly*	*Very unclearly*

11. How competent and knowledgeable was the person with whom you have worked closely?

1	2	3	4
Poor abilities at best	*Only of average ability*	*Competent and knowledgeable*	*Highly competent and knowledgeable*

12. How would you rate the quality of service you have received?

4	3	2	1
Excellent	*Good*	*Fair*	*Poor*

13. In an overall, general sense, how satisfied are you with the service you have received?

4	3	2	1
Very satisfied	*Mostly satisfied*	*Indifferent or mildly dissatisfied*	*Quite dissatisfied*

14. If a friend were in need of similar help, would you recommend our program to him or her?

1	2	3	4
No, definitely not	*No, I don't think so*	*Yes, I think so*	*Yes, definitely*

15. Have the people in our program generally understood the kind of help you wanted?

1	2	3	4
No, they misunderstood almost completely	*No, they seemed to misunderstand*	*Yes, they seemed to generally understand*	*Yes, they understood almost perfectly*

16. To what extent has our program met your needs?

4	3	2	1
Almost all of my needs have been met	*Most of my needs have been met*	*Only a few of my needs have been met*	*None of my needs have been met*

17. Have your rights as an individual been respected?

1	2	3	4
No, almost never respected	*No, sometimes not respected*	*Yes, generally respected*	*Yes, almost always respected*

18. If you were to seek help again, would you come back to our program?

1	2	3	4
No, definitely not	*No, I don't think so*	*Yes, I think so*	*Yes, definitely*

SAMPLE FORM
DO NOT USE

The *Client Satisfaction Questionnaire (CSQ)* was developed by Drs. Clifford Attkisson and Daniel Larsen in collaboration with Drs. William A. Hargreaves, Maurice LeVois, Tuan Nguyen, Robert E. Roberts and Bruce Stegner. Every effort has been made to publish information and research on the CSQ for widest possible dissemination.

saawww.ucsf.edu/csq

UCSF University of California, San Francisco

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CSQ - 31 - 31 Item Client Satisfaction Questionnaire - a combination of the two 16 item versions - First eight items form CSQ-8

1. How satisfied are you with the amount of help you have received?

1	2	3	4
Quite dissatisfied	Indifferent or mildly dissatisfied	Mostly Satisfied	very satisfied

2. Have the services you have received helped you to deal more effectively with your problem?

4	3	2	1
Yes, they helped a great deal	Yes, they helped somewhat	No, they really didn't help	No, they seemed to make things worse

3. How would you rate the quality of the service you have received?

4	3	2	1
Excellent	Good	Fair	Poor

4. In an overall, general sense, how satisfied are you with the service you have received?

4	3	2	1
Very Satisfied	Mostly Satisfied	Indifferent or mildly dissatisfied	Quite dissatisfied

5. To what extent has our program met your needs?

4	3	2	1
Almost all of my needs have been met	Most of my needs have been met	Only a few of my needs have been met	None of my needs have been met

6. Did you get the kind of service you wanted?

1	2	3	4
No, definitely not	No, not really	Yes, generally	Yes, definitely

7. If you were to seek help again, would you come to our program?

1	2	3	4
No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely

8.If a friend were in need of similar help, would you recommend our program to him or her?

1	2	3	4
No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely

9. You came to our program with certain problems. How are these problems now?

1	2	3	4
Worse or much worse	No change	Somewhat better	A great deal better

10. How convenient is the location of our building?

4	3	2	1
Very convenient	Mostly convenient	Somewhat inconvenient	Very inconvenient

11. In general have the receptionists and secretaries seemed friendly, and made you feel comfortable?

4	3	2	1
Yes, definitely	Yes, most of the time	No, sometimes not	No, often not

12. Have the services you received led to any changes in either your problem or yourself?

1	2	3	4
Yes, but the changes were for the worse	No, there was really no noticeable change	Yes, some noticeable change for the better	Yes, a great deal of positive change

13. Are you satisfied with the fee charged for the services you received?

1	2	3	4
Quite dissatisfied	Indifferent or mildly dissatisfied	Mostly Satisfied	Very Satisfied

14. Do you feel that our program has kept your problems confidential?

4	3	2	1
Yes, I feel they definitely have	Yes, I feel they have	No, I feel they have not	No, I feel they definitely have not

15. When you first came to our program, did the receptionists and secretaries seem friendly and make you feel comfortable?

4	3	2	1
Yes, they definitely definitely did	Yes, they generally did	No, they generally didn't	No, they definitely didn't

16. Have you received as much help as you wanted?

1	2	3	4
No, definitely not	No, not really	Yes, generally	Yes, definitely

17. How interested have the receptionists and secretaries been in helping you?

4	3	2	1
Very interested	Interested	Somewhat uninterested	Very uninterested

18. How interested in helping you was the person with whom you have worked most closely?

4	3	2	1
Very interested	Interested	Somewhat uninterested	Very uninterested

19. When you first came to our program, were you seen as promptly as you felt necessary?

4	3	2	1
Yes, very promptly	Yes, promptly	No, there was some delay	No, it seemed to take forever

20. In general, how satisfied are you with the comfort and attractiveness of our facility?

1	2	3	4
Quite dissatisfied	Indifferent or mildly dissatisfied	Mostly Satisfied	very satisfied

21. Did the characteristics of our building detract from the services you have received?

1	2	3	4
Yes they detracted very much	Yes, they detracted somewhat	No, they did not detract much	No, they did not detract at all

22. Considering your particular needs, how appropriate are the services you have received?

4	3	2	1
Highly appropriate	Generally appropriate	Generally inappropriate	Highly inappropriate

23. When you talked to the person with whom you worked most closely, how closely did he or she listen to you?

1	2	3	4
Not at all closely	Not too closely	Fairly closely	Very closely

24.Have you ever felt that out program was more concerned with procedures than with helping you?

4	3	2	1
Concerned mostly with helping me	Concerned more with helping me	Concerned more with procedures	Concerned mostly with procedures

25. Were there other services you needed, but did not received?

1	2	3	4
Yes, there definitely were	Yes, I think there were	No, I don't think there were	No, there definitely were not

26. How clearly did the person with whom you worked most closely understand your problem and how you felt about it?

4	3	2	1
Very clearly	Clearly	Somewhat unclearly	Very unclearly

27. How competent and knowledgeable was the person with whom you have worked closely?

1	2	3	4
Poor abilities at best	Only of average ability	Competent and knowledgeable	Highly competent and knowledgeable

28.How satisfied are you with the kind of service you have received?

1	2	3	4
Quite dissatisfied	Indifferent or mildly dissatisfied	Mostly Satisfied	Very Satisfied

29. Have the people in our program generally understood the kind of help you wanted?

1	2	3	4
No, they	No, they seemed	Yes, they seemed	Yes, they

misunderstood almost completely	to misunderstand	to generally understand	understood almost perfectly

30. Have your rights as an individual been respected?

1	2	3	4
No, almost never respected	No, sometimes not respected	Yes, generally respected	Yes, almost always respected

31.How satisfied are you with the quality of service you have received?

4	3	2	1
Very Satisfied	Mostly Satisfied	Indifferent or mildly dissatisfied	Quite dissatisfied

7. If you were to seek help again, would you come to our program?

1	2	3	4
No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely

8.If a friend were in need of similar help, would you recommend our program to him or her?

1	2	3	4
No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely

COMPREHENSIVE ASSESSMENT AND REFERRAL EVALUATION

The Comprehensive Assessment and Referral Evaluation (CARE) is an assessment technique which is intended to reliably elicit, record, grade and classify information on the health and social problems of the older person.

The CARE is basically a semi-structured interview guide and an inventory of defined ratings. It covers psychiatric, medical, nutritional, economic and social problems rather than the interests of only one professional discipline. The style, scope and scoring of the CARE makes it suitable for use with both patients and non-patients, and a potentially useful aid in determining whether an elderly person should be referred, and to whom, for a health or social service.

Abbreviated Name: CARE-2000
Author(s): Gurland BJ, Kuriansky JB, Sharpe L, Simon R, Stiller P, Birkett P
Purpose: To comprehensively assess functioning and other qualities of life of elders
Population: Adult and Geriatrics
Type of Instrument: Quality of Life
Mode of Administration:

Rater:	Interviewer-administered
Time required:	20-30 minutes
Response Options:	6-point Likert scale
Scoring:	Global score
Score Direction:	Lower scores show better QoL

Number of Items: 30
Original Language: English
Existing Translations : Spanish

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Contact for information and permission to use:

Barry J Gurland, FRCP, FRCPsych
Columbia University Stroud Center
100 Haven Avenue
Tower 3-30F
New York, NY 10032 USA
Phone: +1 212-781-0600
Fax: +1 212-795-7696
Email: bjg1@columbia.edu

Dimensions covered by the questionnaire :

- Mobility
- Basic Activities of Daily Living
- Technological Activities of Daily Living
- Navigational Orientation
- Continuity Orientation
- Receptive Communication
- Health and Safety Practices
- Emotional and Physical Status
- Engaging in Social Relations
- Exercising Choice
- Managing Material Resources
- Finding the best Environment
- Obtaining Meaningful Gratification
- Self Perceived Health
- Pessimism, Optimism, Realism
- Balancing competing Quality of Life
- Setting and Achieving Goals

Key References:

CORE-CARE:

1. Gurland B, Kuriansky J, Sharpe L, Simon R, Stiller P, Birkett P. The Comprehensive assessment and Referral Evaluation (CARE)-rationale, development and reliability. Int J Aging Hum Dev. 1977-78;8(1):9-42.

The Comprehensive Assessment and Referral Evaluation (CARE) is a new assessment technique which is intended to reliably elicit, record, grade and classify information on the health and social problems of the older person. The CARE is basically a semi-structured interview guide and an inventory of defined ratings. It is designated comprehensive because it covers psychiatric, medical, nutritional, economic and social problems rather than the interests of only one professional discipline. The style, scope and scoring of the CARE makes it suitable for use with both patients and non-patients, and a potentially useful aid in determining whether an elderly person should be referred, and to whom, for a health or social service. The CARE can also be employed in evaluating the effectiveness of that service if given.

SHORT-CARE:

2. Gurland BJ, Wilder DE. The CARE interview revisited: development of an efficient, systematic clinical assessment. J Gerontol. 1984 Mar;39(2):129-37.

This paper introduces a series on a method of systematically assessing the health and social problems of elderly adults, the Comprehensive Assessment and Referral Evaluation (CARE). AN overview is given of the conceptual approach and development of the CARE and its principle features including clinical relevance, semistructured format, criterion-based diagnosis, and psychometric properties as established on a probability sample of the elderly population. The reduction of the CARE is described, from a 1500-item instrument covering a wide range of problem areas and taking 90 minutes to administer, to shorter, more efficient and selective versions, the CORE-CARE and SHORT-CARE. The subsequent papers give details of the properties, reliability, validity, and reduction of the CARE.

3. Gurland B, Golden RR, Teresi JA, Challop J. The SHORT-CARE: an efficient instrument for the assessment of depression, dementia and disability. J Gerontol. 1984 Mar;39(2):166-9.

IN-CARE

4. Mann A, Gurland B, Cross P: A comparison of the long-term care of the elderly in New York and London and implications of the differences. In Radebaugh TS, Gruenberg EM, Kramer M, Cooper B (eds.) The Chronically Mentally Ill: An International Perspective. Baltimore: Johns Hopkins School of Hygiene and Public Health, 1985;117-129.

CLIN-CARE

5. Gurland B, Lantigua R, Teresi J, Holmes D, Barrett V: The CLIN-CARE: A technique for comprehensive assessment: preliminary report of biometric properties. In Wykle ML (ed.) Elderly Rehabilitation as Art and Science. New York: Springer, 1990;78

Informant version

6. Wilder DE, Gurland BJ, Chen J, Lantigua RA, Katz S, Killeffer EHP, Encarnacion P: Interpreting subject and informant reports of function in screening for dementia. International Journal of Geriatric Psychiatry 1994;9:887-896.

ITEMS IN THE CARE AS USED IN THE CARE 2000.

CHARACTERISTICS OF INTERVIEW

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

DEMOGRAPHIC AND PERSONAL INFORMATION

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

Correct age	/# [10a]
Correct year of birth	/# [11a]
Stated birthplace	/# [17a]
Year of immigration	/# [18]
Did not learn to read and write	/1 [19]
Highest grade or year completed	/# [20]
Best information on years at address	/# [22b]
Stated year moved to that address	/# [23a]
Does not have telephone	/1 [24]
Best information on telephone number	/# [25b]

_____

Working	/1 [288]
Retired	/2 [288]
Unemployed	/3 [288]
Never worked	/4 [288]
Working full-time	/1 [289]
Working part-time	/2 [289]
Job title	/codes [290]
Same kind of work did most of life	Yes/1 No/2 [291]
Job title most of life	/codes [292]
Job of spouse most of life	/codes [295]
Joint income	/monthly codes [296]
Mnthly incme jst enough to mk ends mt	/2 [297]
Mnthly incme not enough to mk ends mt	/3 [297]

Ethnic self-description: White	/1 [298]
Ethnic self-description: Black	/2 [298]
Ethnic self-description: Asian	/3 [298]
Ethnic self-description: Other	/4 [298]
Hispanic descent/Country of origin/country codes	[299]
Home language: English	/0 [300]
Home language:Foreign	/1 [300]
Language at home	/?codes [item#?]
Fluency in English: very well	/1,

Fluency in English:wel l/2, [302]
Fluency in English:not well /3, [302]
Fluency in English:not at all /4 [302]
Primary language of interview /codes 0-1 [395]

SOCIAL NETWORK

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx
Married (or living together 7+ years) /1 [51]
Widowed /2 [51]
Divorced/separated /3 [51]
Separated /5 [51]
Never married /4 [51]
Years married /# [52]

Household members: age	=#,
Household members:gender=male	/1
Household members:gender=female	/2,
Hsehld mmbrs:reltnship: Spouse	01
Hsehld mmbrs:reltnship:Son/Daughter	02
Hsehld mmbrs:reltnship:Son/Dghter-in-law	03
Hsehld mmbrs:reltnship:Grandchild	04
Hsehld mmbrs:reltnship:Parent of rspndnt	05
Hsehld mmbrs:reltnship:Brother/Sister	06
Hsehld mmbrs:reltnship:Nephew/Niece	07
Hsehld mmbrs:reltnship:Cousin	08
Hsehld mmbrs:reltnship:Uncle/Aunt	09
Hsehld mmbrs:reltnship:Great grandchild	10
Hsehld mmbrs:reltnship:Other relative	11
Hsehld mmbrs:reltnship:Friend	12
Hsehld mmbrs:reltnship:Boarder, renter	13
Hsehld mmbrs:reltnship:Paid employee	14
Hsehld mmbrs:reltnship:Other unrelated	15

Codes for above:
[53a1 to 53a4] [53b1 to 53b4] [53c1 to 53c4] [53d1 to 53d4] [53e1 to 53e4] [53f1 to 53f4] [53g1 to 53g4] [53h1 to 53h4] [53i1 to 53i4] [53j1 to 53j4] [53k1 to 53k4] [53L1 to 53L4] [53m1 to 53m4] [53n1 to 53n4]

Total # hsehld mmbrs (incld. sbjct) /# [54]

N years living alone /# [55]
Less than one year living alone /1 [55]
N children living /# [58]
N children seen in month /# [59]
N chldrn not seen but contcted phne-lttr /# [60]
N of grandchildren living /# [61]
N of grandchildren seen in month /# [62]
N grndchldrn not seen bt cntct phne-lttr /# [63]
N of sibs living /# [64]
N of sibs seen in month /# [65]
N sibs not seen bt cntct phn-lttr /# [66]
N of other relatives seen in month /# [67]
N othr rltvs not seen bt cntct phn-lttr /# [68]
Didn't use phone in month /2[26]

SOCIAL ISOLATION

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx
Felt lonely in month /1 [56]
Often feels lonely /1 [57]
Does not feel close to anyone /1 [69]
Noone to talk to abt prblms /1 [70]
Usually keeps problems to self /1 [71]
If ill might be unnoticed over 24 hrs /1 [72]

COMMUNICATION PROBLEMS X

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx
No response to vrbl greet. or extnd hnd /1 [1]
No apprpriate rspnse to `how feeling' /1 [2]
No rspnse to greeting or simple qstions /1 [3]
Does not state name at verbal request /1 [4]
Does not state name at written request /1 [5]
Cannot follow simple verbal commands /1 [6]
Cannot follow simple written commands /1 [7]
_____X_____
Keeps forgetting the proper word to use /1 [349]
Repeatedly struggles to find right word /1 [350]

Only understood by othrs with dffculty /1 [348]
Express only w' sign lnguage or writes /1 [351]
Express only w' gestures-grunts-symbols /1 [352]

Has limitd cmprehnsn of oral communic.	/1 [354]
Undrstnds by lip rdng, wrtng, sgn lngge	/1 [355]
Undrstds only gstres, pctgrms, environs	/1 [356]
Rambling or incoherent or irrelevant	/1 [360]
Only moans or repeats one or two words	/1 [363]
Impaired communictn due slurred speech	/2 [366]
Impaird communictn due incohrnce/ramblng	/4 [366]
Impaird comm. due inattentve/stuporous	/5 [366]
Imprd cmm./mentlly inactv-dsn't undrstnd	/6 [366]
_____	
Observ: comm. impdimnt	/Inverse 0-100

DEPRESSION-MOOD X

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

Regrets about past (+ or - justifiable)	/1 [34]
Unjustfiable slf-blame/ past or present	/2 [34]
Unrealistic self-depreciation	/3 [34]
Admits to worries	/1 [35]
Worries about almost everything	/1 [36]
Has been sad or depressed during month	/1 [37]
Sadnss-deprssion lasts over few hours	/1 [38]
Sadnss-deprss most/evry day/two weeks+	/1 [39]
Feels worst beginning of the day	/1 [40]
Feels worst end of the day	/2 [40]
Feels worst all day long	/4 [40]
In month, life was <u>not</u> worth living	/1 [41]
Has cried in past month	/1 [42]
Has felt like crying in month	/1 [43]
Pessimistic, or has empty expectations	/1 [44]
Future looks bleak or unbearable	/2 [44]
In month, rather dead or o end it all	/1 [45]
Wished to be dead but rejects suicide	/1 [46]
Has fleeting suicidal thoughts	/2 [46]
Seriously consdrd/ not attmptd suicde	/3 [46]
Has attempted suicide in month	/4 [46]
Less enjoyment/interest in things	/1 [47]
Almost nothing enjoyed in month	/1 [48]
Enjymnt/intrst lost due deprssd/nervous	/1 [49]
Doesn't recall being happy in month	/1 [50]
More irritable-angry than usual	/1 [73]
Hostile, irritable	/1 [390]

DEPRESSION-SOMATIC X

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

Lost wght in 3 m. amnt uncertain	/1 [74]
Lost wght in 3 m. less than 10 pounds	/2 [74]
Lost wght in 3 m. 10 or more pounds	/3 [74]
Not eating well in month	/1 [75]
Poor apptt NOT due obvious med-dent-naus	/2 [76]
Gained wght in 3 m. uncertain ammount	/1 [77]
Gained wght in 3 m. less than 10 pounds	/2 [77]
Gained wght in 3 m. 10 pounds or more	/3 [77]

Trouble falling/staying asleep in month	/1 [84]
Medication for sleep in month	/1 [85]
Lies awake w' deprssd-anxs feelngs-thts	/1 [86]
Wakes 2 hrs early/ can't return sleep	/1 [89]
Wakes up feeling tired	/1 [90]
Naps during the day (more than 2 hours)	/1 [91]

Sometime trembling in month	/1 [124]
Recently not enough energy	/1 [125]
Felt slowed physically in month	/1 [126]
Doing less than usual in month	/1 [127]
Any slowness is worse in morning	/1 [128]
Sits around a lot for lack of energy	/1 [129]?
Admits to being restless	/1 [130]
Speech very rapid/ difficult to follow	/1 [357]
Speech very slow, long pauses	/1 [358]
Restricted in quantity	/1 [359]
Could undrstnd intervw but answrd slowly	/2 [393]
Slow undrstnd intrvw/ diffic. answerng	/3 [393]

Dstrss-lnly-brd-frust by limit going out	/1 [186]
In month, medic/inj for other ment-emot	/1 [131g]
Looks sad, mournful, tearful, gloomy	/1 [382]
Lability, rapid changes in mood	/1 [383]
Slowness, underactivity	/1 [388]

SUBJECTIVE MEMORY COMPLAINTS

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

S-Diffclty remmbering just read or heard	/1 [93a]
S-Diffclty remmbering names family/frnds	/1 [93b]
S-Stopped by prblems remmbring right wrd	/1 [93c]
S-Diffclty doing thngs due other memory	/1 [94]
S-Memry mks diff to go outside by self	/1 [95a]
S-Memry mks diff to shop	/1 [95b]
S-Memry mks diff to get house chores done	/? [95c]
S-Memry mks diff to track persnl busnss	/1 [95d]
More difficult remembering than before	/? [96]

COGNITIVE IMPAIRMENT

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

Discrpncy scr: statd v best ys at addrss	/# [22a] v /# [22b]
Discrpncy scr: statd v best teleph #	/# [25a] v /# [25b]
Does not spell both names correctly	/1 [8]
Can't repeat rtr's name aft 3 repeats	/1 [9]
Age not stated/incorrect/doesn't know	/1 [10b]
Yr of brth not statd/incrrect/dn't knw	/1 [11b]
Mnth birth not statd/incrrect/dn't knw	/1 [12b]
Date birth not statd/incrrect/dn't knw	/1 [13b]
Don't corrct/explain brth-age discrpncy	/1 [14]
Marked uncertnty about age and birthdte	/1 [15]
Stated birthdte-age obviously wrong	/1 [16]
Birthplce not statd/incorrect/doen't knw	/1 [17b]
Don't give corrct answr /street name	/1 [21a]
Don't give corrct answr /street number	/1 [21b]
Don't give corrct answr /city	/1 [21c]
Don't give corrct answr /state	/1 [21d]
Don't give corrct answr /zip code	/1 [21e]
Doesn't know how long at that address	/1 [22c]
Length of resdnce incorrct/don't knw	/1 [23b]
Telphne # not knwn/incmplt/from record	/1 [25c]
Used help dialing telephone # in month	/1 [26]
Don't telephne/don't pick up if rings	/1 [27]
Don't identify/know type of place	/1 [28]
Does not state correct floor	/1 [29]
Cannot recall occupation	/1 [293]
Someone reminds time-amnt of medication	/1 [132]
Someone gives medications	/2 [132]

Don't remembr rater's name	/1 [97]
Don't remmber rater's name/ delayed	/1 [117]
Count 1-20: Self-corrected errors	/1 [100]
Count 1-20: Uncorrctd errrs/says can't	/2 100]
N of 3 objects NOT recalled	/# [101]
Can't repeat 3 objcts aft 5 more trials	/1 [102]
N of 3 objects NOT recalled/ delayed	/# [112]
N errors spelling world backwards	/# [103]
Any error or says can't write sentence	/1 [114]
Incrrct President's name or don't knw	/1 [104]
Incrrct past Presdnt's name or don't knw	/1 [105]
Error in date or doesn't know	/1 [106]
Incorrct day of month doesn't know	/1 [107]
Incorrect month or doesn't know	/1 [108]
Incorrect year or dosn't know	/1 [109]
Incrrect day of week or doesn't kow	/1 [110]
Incorrect pat of day or doesn't know	/1 [111]
N errors in folding paper	/# [113]
Error in copying pentagons or says can't	/1 [116]
Glb: severity intellctl imprmnt	/Inverse 0-100 [371]

Performance test of cognitive impairment:

****

Btl: Reclls N pills on 2nd trial	/1 [133]
Btl: Reclls N pills on 3rd trial	/2 [133]
Btl: Don't recll N pills 3rd trial	/3 [133]
Btl: Don't subtract pills correctly	/1 [134]
Btl: Don't crrctly calclte pills lastng	/1 [135]
Btl: Incrrect start day pll regime	/1 [136a]
Btl: Incrrect start day pll regime trl 2	/1 [136a]
Btl: Prompting pill regime	/1 [136b]
Btl: Prompting pill regime trl2	/1 [136b]
Btl: N errors, schedule pill regime	/6-# [136c]
Btl: N errors, schedule pill regime tr 2	/6-# [136c]
Btl: Don't pick bottle as described	/1 [138]
Btl: Don't pick bottle as described tr 2	/1 [139
Btl: Don't pick bottle as described tr 3	/1 [140]
Btl: Don't remove pills as instructed	/1 [141]
Btl: Don't replace 3 pills as instructed	/1 [142]
Btl: Don't replace bottle as instructed	/1 [143]
Btl: 2 trials learn about delayed action	/2 [144]
Btl: 3 trials learn about delayed action	/3 [144]
Btl: Don't learn about delayed action	/4 [144]
Btl: Unprmptd delayd pick bttl error	/1 [147a]
Btl: Unprmptd delayd pick pills error	/1 [147b]
Btl: Prompted delayd pick bttl error	/1 [148a]
Btl: Prompted delayd pick pills error	/1 [148b]
Btl: 2nd prompt: delayd pick bttl error	/1 [149a]
Btl: 2nd prompt: delayd pick pills	/1 [149b]
Btl: N deficts describing designtd bttl	/6-# [145]
Btl: N deficts describing designtd plls	/3-# [146]

N errors touching ears with hands	/# [211a]
Hand-ear tst hesitnt/ self-corrections	/1 {212b]

PAIN

****

Has arthritis or rheumatism	/1 [151]
Pain-stffnss-swlling of joints	/1 [152]
Pain-stffnss-swlling of muscls-tendns	/1 [153]
Pain in legs-feet	/1 [154]
Pain-swelling in arms-hands	/1 [155]
Backaches-neckaches	/1 [156]
Headaches	/1 [157]
Freqnt *other* aches-pns not localised	/1 [158a]
Freqnt *other* aches-pains specific prts	/1 [158b]
Pain stops ordinary activities	/1 [159]
Often takes medication to relieve pain	/1 [160]
Trouble with feet (pain-discomfort)	/1 [205]
Med-inj: arthritis-joint-muscle pains	/1 [131e]
Lies awake with pain/ other discomfort	/1 [88]
Dffclty/assist/devce wlkng-pain lgs-ft	/1 [188f]
Obs: evidently in physical pain	/1 [334]

RESPIRATORY

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Had cough in month	/1 [177]
Cough lasted more than 3 weeks	/1 [176]
Short of breath in month	/1 [161]
Breathless all the time	/1 [162]
Breathless when lying flat in bed	/1 [163]
Brthlssnss even sitting up/uses pillow	/1 [164]
Breathless on slight exertion	/1 [165]
Dffclty/assstnce/devce wlking-brthlssnss	/1 [188d]
Med med-inj: other lung or chest condition	/1 [131c]

FAINT-PALPITATION

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

Faintness-rising/relieved sitting-lying	/1 [120]
Felt heart pounding in month	/1 [121]
Pounding prolonged	/1 [122]
Pounding with minor exertion	/1 [123]
Fainted-lost consciousness in month	/1 [118]
Felt dizzy or weak in month	/1 [119]

CARDIOVASCULAR

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Ever had heart trouble	/1 [166]
S-`symptoms' of heart trouble in month	/1 [167]
Ever had high blood pressure	/1 [168]
Chst pn-dscmfrt on exrtion	/1 [169]
Chst pn-dscmfrt on slight exertion	/1 [170}
Chst pn-dscmfrt relved by rst-med	/1 [171]
Chst pn-dscmfrt cntnuos-hvy-grppng-cntrl	/1 [172]
Dffclty/assstnce/devce wlking-pn in chst	/1 [188e]
Med-inj: heart condition	/1 [131a]
Med-inj: hypertension	/1 [131b]

PERIPHERAL VASCULAR

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Cramps in leg on exertion	/1 [173]
Leg cramps relieved by few minutes rest	/1 [174]

EFFORT TOLERANCE

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Must rest after 2 flights of stairs	/1 [194]
Must rest after 1 flight of stairs	/2 [194]
Can't climb 1 flight strs without rsting	/3 [194]
Must rest after walking 6 to 10 blocks	/1 [201]
Must rest after walking 5 blocks	/2 [201]
Must rest after walking 4 blocks	/3 [201]
Must rest after walking 3 blocks	/4 [201]
Must rest after walking 2 blocks	/5 [201]
Must rest after walking 1 blocks	/6 [201]
Must rest befre complting even 1 blck	/7 [201]

PARKINSON'S DISEASE

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People comment voice is softer	/1 [216]
People comment face is less expressive	/1 [217]
Arms-legs shake	/1 [218]
Told that has Parkinson's disease	/1 [220]
Ever taken L-dopa or Sinemet	/1 [221]
Handwriting smaller than it once was	/1 [115]
Has trouble arising from a chair	/1 [215]
Trouble buttoning	/1 [219]
Med-inj: Parkinson's disease	/1 [131f]
Obs: marked difficulty getting up	/1 [335]
Obs: long pause before starting get up	/1 [336]
Obs: very slow in standing up	/1 [337]
Obs: struggles/unable start-stop walking	/1 [338]
Obs: unusual slown-stiff walking	/1 [339]
Obs: unsteady walking unassisted	/1 [340]
Obs: sways in turning around	/1 [341]
Obs: Unusual movements (e.g. writhing)	/1 [342]

STROKE

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Ever had stroke/ministroke-CVA-TIA	/1 [214a]
Called stroke-CVA-TIA by doctor	/1 [214b]
Stroke/CVA/TIA in pat year	/1 [214c]
Ever sudden paralysis-numbness on side	/1 [214c]
Ever sudden lss spch (incohrnt, slurrd)	/1 [214e]
Ever uncnsciousnss with hdache-vomting	/1 [214f]
Stroke-symptoms lasted over 24 hours	/1 [214g]
Stroke symptoms have persisted	/1 [214h]
Slurred speech	/1 [361]
Svere dysarthria/ unintllgble-grammaticl	/1 [362]
Dffclty/assstnce/devce due paralysis	/1 [188b]
Impaird comunictn due can't find words	/3 [366]
Obs: marked one sided paralysis	/1 [332]
Obs: marked one sided weakness	/1 [333

HEARING

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Claims difficulty hearing	/1 [227]
Usually wears a hearing aid	/1 [228]
Can't hear-understnd ordinry convrsation	/1 [229]
Ask people to repeat things	/1 [230]
Asks people to speak louder	/1 [231]
Can't follow convrsation in small group	/1 [232]
Can't hear telephone ring in same room	/1 [233]
Can't hear convrsation on telephone	/1 [234]
Obs: diffculty hearing during interview	/1 [235]
Obs: interviewer must raise voice	/1 [236]
Obs: interviewer must shout	/2 [236]
Some difficulty hearing interviewer	/1 [346]
Interviewer must speak very loud	/2 [346]
Interviewer must shout	/3 [346]
Observer rating of hearing	/1 Inverse 0-100 [347]
Impaired comunication due deafness	/1 [366]

VISION

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Usually wears glasses or contact lenses	/1 [237]
Trouble seeing (with eyeglasses on)	/1 [238
Difficlty vision makes difficlt doing	/1 [239]
Can't read regular print newspprs-lttrs	/1 [240]
Can't read the telephone directory	/1 [241]
Can't read labels or prices in shops	/1 [242]
Can't recognize people on the street	/1 [243]
Problems hear-see interfre w' doing	/1 [244]
Difficlty w' items relying on vision	/1 [344]
Can't perform tasks requiring vision	/2 [344]
Items relying on vision contraindicated	/3 [344]
Obs: rating of vision	/1 Inverse 0-100 [345]

GENERAL WELL BEING

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Slf-percved physcl hlth/ age peer /Good	/2 [31]
Slf-percved physcl hlth/ age peer /Fair	/3 [31]
Slf-percved physcl hlth/ age peer /Poor	/4 [31]
Satsfctn w' life genrlly-presntly /Fair	/2 [32]
Satsfctn w' life genrlly-presntly /Poor	/3 [32]
Happiness generally /Fairly happy	/2 [33]
Happiness generally /Not very happy	/3 [33]
Happiness generally /Not happy at all	/4 [33]
Hlth interfrs w' doing	/1 [245]
Hlth interfrs w' doing/ a great deal	/1 [246]
Hlth interfrs w' doing/ some other way	/1 [248i]
Med-inj: diabetes	/1 [131d]
Med-inj: any other condition	/1 [131h]
Retired due to health reasons	/1 [294]
Health interferes paying job	/1 [248d]
Brthlss-pndng-exrtn-pn interfre actvties	/1 [247]
Overall health-*limitation* getting worse	/2 [249]
Overall health-limitation remaining same	/3 {249]
Poor appett/ due obvious med-dent-naus	/1 [76]
Dffclty/assstnce/devce wlking-gnrl wknss	/1 [188a]
Dffclty/assstnce/devce wlking-oth physic	/1 [188h]
Dffclty/assstnce/dvce wlkng-oth non-phys	/1 [188i]
Had a growth or tumor in 5 years	/1 [212]
MD called malignnt-cancer-serious	/1 [213]

ILLNESS EPISODES

****

Ill in bed at home during year	/1 [304]
N of days ill in bed at home in year	/# [307]
Went to the emergency room in year	/1 [308]
N of visits to the emergency room	/# [309]
Has been in hospital overnight in year	/1 [310]
Admitted to specific hospitals in year	/hospital codes [311a-g]
N of stays in hospital in year	/# [312]
N of days in hospital in year	/# [313]
Overnight for operatn in last 5 years	/1 [314]
Had operation in the past year	/1 [315]
Movement affected-limited by operation	/1 [316]
Stayed in nursing home in year	/1 [317]
N of weeks in nursing home in year	/# [318]

MOBILITY

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Transfers with device only	/1 [177]
Transfers with assistance only	/2 [177]
Transfers with device and assistance	/3 [177]
Transferred passively	/5 [177]
Does not transfer (bedfast or chairfast)	/6 [177]
Difficulty walking indoors	/1 [178]
Someone helps walking indoors	/1 [179]
Difficulty walking outdoors	/1 [180]
Someone helps walking outdoors	/1 [181]
N of days did not go out in week	/7-# [182
Has not gone out of doors in month	/1 [183]
Not out doors except in wheelchair	/1 [184a]
Not out doors except w' asssted wlking	/1 [184b]
Not out of doors as often as needs	/1 [185]
Usually uses a walker to help walk	/1 [187a]
Usually uses a cane to help walk	/1 [187b]
Used a wheelchair to get around	/1 [187c]
Feet suddenly seem to freeze in doorwys	/1 [189]
Shuffles feet-takes tiny steps walking	/1 [190]
Claims that Balance is poor	/1 [190a]
Dffclty wlkng-gttng arnd intrfrs wants	/1 [191]
Obs: difficulty walking as directed	/1 [192]
Obs: wheelchair bound-chairbound	/1 [193]
Observed bed bound	/2 [193]
Obs: walking w' cane or walker only	/1 [343]
Obs: walking personal assistance only	/2 [343]
Obs: walking device and help of person	/3 [343]
Obs: walking does not walk	/4 [343]
Obs: walking - contraindicated	/5 [343]
Hlth interfrs getting arnd outside home	/1 [248e]
Hlth interfrs travel outsde neighborhd	/1 [248g]

Cannot get off a bus or train by self	/1 [195]
Cannot manage heavy doors	/1 [196]
Diffclty crossing rds-intersctns by slf	/1 [200]
Not traveled outside neighborhd in mnth	/1 [202]
Travld outsde neighborhd by specl vehicl	/2 [203]
Travld outsde neighborhd by ambulance	/3 [203]
Travld outsde neighborhd w' pers assistnc	/1 [204]
Dffclty-assstnce-dvce wlkng/ stiff-stoop	/1 [188g]

FALLING AND FRACTURES

****

Admits ever trips and falls	/1 [197]
N of falls year	/# [198]
Due flling rsk changed 1+ activity	/1 [199]
Due flling rsk stopped 1+ activity	/2 [199]
Due flling rsk chnged-stoppd 1+ activty	/3 [199]
Dffclty-assstnce-dvce wlkng/ poor balnce	/1 188c]

Has broken bones, since becoming adult	/1 [222]
Broken bones in last 10 years	/1 [223]
Broken bones in last year	/? [224]
Has aftereffects of broken bones	/1 [225]
Limited movemnt by aftereffcts fracture	/1 [226]

RANGE OF MOTION

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Difficulty cutting toenails by self	/1 [206]
Someone helps cut toe nails	/1 [207]
Obs: can't touch toes w' both hands	/1 [208]
Obs: can't lift both arms over head	/1 [209]
Obs: can't reach left hand behind back	/1 [210]
Obs: can't reach rigt hand behind back	/2 [210]
Obs: can't reach either hand behind back	/3 [210]

BADL

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Problems-difficulties bath-shower slf	/1 [253]
Bathes-shower slf, nds someone prsent	/1 [254]
Assistd bathing, only one part of bdy	/2 [254]
Assistd bthing, svrl prts/in-out/run wtr	/3 [254]
Assistd bthing, all prts, partcpates	/4 [254]
Totally dependent bathing	/5 [254]
Prblms-diffclts getting to toilet slf	/1 [255a]
Prblms-diffclts using toilet by self	/1 [255b
Assisted getting to and from the toilet	/? [256]
Assisted to use the toilet	/1 [257]
Used a commode or bedpan in month	/1 [258]
Assisted use commode or bedpan in mnth	/1 [259

Lost control of bladder in month /1 [260]
Exertion incontinence in month /1 [261]
Lost control of bowels /1 [262]

Problems-difficulties dressing by self /1 [270]
Problems-difficulties brushing hair slf /1 [271]
Females: problems with using cosmetics /1 [272]
Males: problems with shaving /1 [272]
Some dressing-grmng slf, others do rest /1 [274]
Almst no drssng-grming slf, prticipates /2 [274]
No dressng-grming slf, others do it /3 [274]
Drssing-grming assist only tying shoes /1 [275]
Assisted dressing, or stays undressed /2 [275]
Feeds self, assist cutting-buttering /1 [276]
Assistd feeding/tube fed/intravenous /2 [276]
Claims more help with personal care /1 [277]
Needed additnl prsnl care unavailable /1 [278]
Difficulty getting additional prsnl care /?1 [279]

IADL

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Diffclty w' light chres/ dshes-stve-grbg /1 [263]
Many light chrs slf, othrs do rest /1 [264]
Few light chrs slf, others do rest /2 [264]
Almost no light chres slf/ may partcpate /3 [264]
Dffclty w' heavy chres/ sweep, tub, shts /1 [265]
Many heavy chres slf, others do rest /1 [266]
Few heavy chores by self, others do rest /2 [264]
Almost no heavy chrs slf/ may particpate /3 [264]
Difficulties leave some chores undone /1 [267]
Undone chores cause problems /1 [268]
Claims needs *more hlp* w' househld chres /1 [269]
Health interferes light chores /1 [248b]
Health interferes heavy chores /1 [248c]

Prblms-dffclties w' laundry/getting done /1 [280]
Hand wshed laundry slf, others do rest /1 [2881]
Almost no laundry slf/ prepares-arranges /2 [281]
No laundry slf, arranged-done by others /3 [281]

Diffclty preparing-cooking meals by self /1 [78]
Prprng-cking mls: most slf, othrs rest /1 [79]
Prprng-cking mls: some slf, othrs rest /2 [79]
Prprng-cking mls: none/almost none slf /3 [79]
Could prpr-ck mls if must: probably /1 [80]
Could prpr-ck mls if must: probably not /2 [80]
Could prpr-ck mls if must: defntely not /3 [80]
Diffclty-problms doing shopping by self /1 [81]
Shoppng: Most slf, others do rest /1 [82]
Shoppng: some slf, others do rest /2 [82]

Shoppng: none/ almost none slf	/3 [82]
Could shop if must: probably	/1 [83]
Could shop if must: probably not	/2 [83]
Could shop if must: definitely not	/3 [83]
Hlth interfrs w' carrying heavy packges	/1 [248f]
Problms-diffclty handling persnl busnss	/1 [250]
Don't pay bills-rent-get cash slf	/1 [251]
Help w' paying bills-rent-getting cash	/1 [252]
Help w' paying bills-rent-getting cash	/2 [252]

SOCIAL DISENGAGEMENT

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NO: knitting, music, other hobby	/1 [282a]
NO: walking (for pleasure) or excursion	/1 [282b]
NO: visiting friends or relatives	/1 [282c]
NO: being visited by relatives-friends	/1 [282d]
NO: physical conditioning	/1 [282e]
NO: going to movie-restrnt-sportng evnt	/1 [282f]
NO: reading magazines-newspapers-books	/1 [282g]
NO: watching TV or listening to radio	/1 [282h]
NO: unpaid community-volunteer work	/1 [282i]
NO: playing cards-games-bingo	/1 [282j]
NO: going to a club or center	/1 [282k]
NO: going to classes	/1 [282l]
NO: going to church-synagogue-temple	/1 [282m]
Hlth interfrs desired leisure activities	/1 [248a]
Hlth interfrs vistng-social activities	/1 [248h]

SERVICES USE

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Not consulted doctr or clinic in year	/0 [303]
Not convenient to get to doctor-clinic	/1 [304]
Physic conditn make dffclt get MD/clinic	/1 [305]
In yr used: specl transprttion-elderly	/1 [319]
In yr used: Senior Center/ not meals	/1 [320]
In yr used: meals on wheels at home	/1 [321]
In yr used: hmecre srvce/ nrse, hmemkr	/1 [322]
N of hours per week of home service	/# [323]
Hlth insrnce: Medicare Part B	/1 [324a]
Hlth insrnce: Medicaid	/1 [324b]
Hlth insrnce: additnl prvt hlth insur	/? [324c]

APPEARANCE

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Signs respondent has been abused	/1 [369]

_____

Neglected appearance	/1 [381]
Lack of spontaneous emotion, monotonous	/1 [384]
Problm stayng alert-paying attention	/1 [385]
Behaves as hearing voices, sees visions	/1 [386]
Restless, fidgeting, pacing	/1 [387}
Suspiciousness	/1 [389]

_____

Persnl appearnce fairly neat and clean	/2 [394]
Personal appearance not neat and clean	/3 [394]

CRIME EXPERIENCE

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Neighborhood somewhat safe from crime	/2 [282]
Neighborhood not too safe	/3 [282]
Neighborhood not safe at all	/4 [282]
In year has been mugged-attacked	/1 [284a]
In year has had wallet/purse snatched	/1 [284b]
In year has had mailbox broken into	/1 [284c]
In year has had apartment robbed	/1 [284d]
Crime stoppd socl actvties/ visit, club	/1 [285]
Avoids going out alone in day/ crime	/1 [286]
Avoids going out alone at night/ crime	/1 [287]

NEIGHBORHOOD

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Buildng apprs somewht dangerous-crime	/2 [391]
Buildng apprs very dangerous-crime	/3 [391]
Dwellng unit fairly neat and clean	/2 [392]
Dwelling unit not too neat and clean	/3 [392]

CARE TOOL - PROVIDER ASSESSMENT

PATIENT:	SSN:	DATE:

AREAS OF CONCERN	1	2	3	4	5	6
DIAGNOSIS OR SYSTEMIC DISTURBANCE	None	Subclinical	(1) DX mild to moderate	(2) Diagnoses	Severe Limits to activities for daily living, limit ADLs	Life-threatening
PAIN AND/OR SOB	None	Intermittent. No Rx	Intermittent. Requires Rx.	Constant. Controlled with Rx	Limits ADLs	Constant, Uncontrollable
NUMBER OF MEDICATIONS	None	1-2	3-4	5-6	3-6 with history of adverse reactions	>6
NUTRITION (ALBUMIN AND BODY WEIGHT)	3.5 or > 1-5 lbs over/under normal weight	3.5, or >1-10 lbs over/under normal weight	3.5, or >1-15 lbs over/under normal weight	3.49 - 3.1	3.0 to 2.5	2.9 or less
URINATION	Intact	Symptoms of frequency or urgency	Aware; Occasional accidents/Nocturia >2 times	Aware; Daily accidents	Unaware; Daily accidents	Catheter
DEFECATION	Q 3 day, no clinical symptoms	Q 3 day with history of diarrhea or constipation	Q 3 day with symptoms of diarrhea or constipation	> Q 3 day	Aware; Impacted or incontinent	Unaware; Impacted or incontinent
COGNITION	Intact	Mild short-term memory loss	Moderate short-term memory loss	Severe short-term memory loss	Acute confusional state; Hallucinations	Unresponsive
EMOTION	Intact	History of anxiety/depression	Symptoms of anxiety	Symptoms of depression	Vegetative state: Sleep, appetite and energy disorder	Psychotic; Hallucinations
MOBILITY	Intact & regularly exercising	Intact; Driving car or using public transportation	Independent ambulation in neighborhood; and or walker or cane	Independent ambulation in home only; &/or walker or cane	Requires 1 person assist	Requires 2 person assist
CARE PLAN MAINTENANCE	No Active Problem	Initiates problem identification	Actively cooperates	Passively cooperates	Passively uncooperative	Actively uncooperative
SELF CARE	Independent	Requires assistance with meals	Requires assistance with bathing	Requires assistance with dressing	Requires assistance with toileting	Requires assistance with feeding
HEALTH RATING	1- Excellent	2	3	4	5	6- Poor

COOP/WONCA CHARTS

The Dartmouth Primary Care Cooperative Information Project (COOP) chart system has been developed and refined for over a decade for the purpose of making a brief, practical and valid method to assess the functional status of adults and adolescents. The system was developed by the Dartmouth COOP Project, a network of community medical practices that cooperate on primary care research activities.

The charts are similar to Snellen charts, which are used medically to measure visual acuity quickly in busy clinical practices. Each Chart consists of a title, a question referring to the status of the patient over the past 2-4 weeks, and 5 response choices. Each response is illustrated by a drawing that depicts a level of functioning or well-being along a 5 point ordinal scale. The illustration makes the Charts appear "friendly" without seeming to bias their responses.

In accordance with clinical convention, high scores (i.e., patient rating of 4 or 5) represent unfavorable levels of health (life quality or social support) on each respective Chart. For example, Physical Chart responses range from 1 to 5 with a score of 5 representing major limitations.

The Charts are a simple, easily administered, self-scoring system for screening, assessing, monitoring and maintaining patient function. This system has been tested in many different practices, in both North America and elsewhere, to evaluate and establish its reliability, validity and acceptability. One set of the Charts -the WONCA version for adults- has been developed as the international standard for classifying the functional status of adult medical patients in primary care settings. The COOP/WONCA version of the charts which differ somewhat from the original COOP Charts by asking about function in the previous 2 weeks (rather than 4 weeks). The dimensions of health status measured by the health charts are: Physical, Emotional, Daily Activities, Social Activities, Social Support, Pain, and Overall Health. The adult Charts have been used widely.

Abbreviated Name: COOP/WONCA
Author(s): Eugene C. Nelson, John H. Wasson
Purpose: To measure the patients' overall functional health
Population: Adult
Age Range : 12+ years
Type of Instrument: Quality of Life
Mode of Administration:

Rater:	Self-administered
Time required:	1-3 minutes
Response Options:	Likert scale with drawings
Scoring:	Global score
	Scores by dimension
	Scores by items
Score Direction:	Lower scores show better QoL (evident from each measure)

Number of Items: 6
Original Language: English
Existing Translations : Arabic, Chinese, Danish, Dutch, Finnish, French, German, Hebrew, Italian, Japanese, Korean, Norwegian, Portuguese, Slovak, Spanish, Swedish, Urdu

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Contact for information and permission to use:

Deborah J. Johnson
Dartmouth COOP Project
Dartmouth Medical School,
Butler Building, HB 7265
Hanover, NH 03755 USA
Phone: 603.650-1220
Fax: 603.650-1331
E-mail: Deborah.Johnson@dartmouth.edu

Dimensions covered by the questionnaire :

- Physical
- Emotional
- Social support
- Social Activities
- Daily Activities
- Pain
- General health

Existence of a scoring/interpretation/user manual : Yes.
Key References:

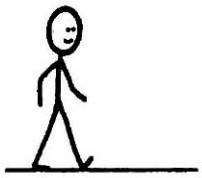
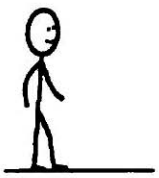
1. Nelson EC, Wasson J, Kirk J, et. al. Assessment of Function in Routine Clinical Practice: Description of the COOP Chart Method and Preliminary Findings. Journal of Chronic Diseases 1987; 40(S1):55S-63S

The COOP Project, a primary care research network, has begun development of a Chart method to screen function quickly. The COOP Charts, analogous to Snellen Charts, were pretested in two practices on adult patients (N = 117) to test feasibility, clinical utility, and validity. Patients completed questionnaires containing validated health status scales and sociodemographic variables. Practice staff filled out forms indicating COOP Chart scores and clinical data. We held debriefing interviews with staff who administered the Charts. The results indicate the Charts take 1-2 minutes to administer, are easy to use, and produce important clinical data. The patterns of correlations between the Charts and validity indicator variables provide evidence for both convergent and discriminant validity. We conclude that new measures are needed to assess function in a busy office practice and that the COOP Chart system represents one promising strategy.

COOP/WONCA charts

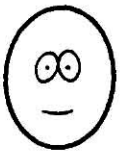
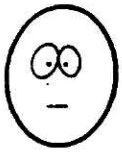
Physical fitness

During the past 2 weeks…
What was the hardest physical activity you could do for at least 2 minutes?

Very heavy, (for example) run, at a fast pace	**1**
Heavy, (for example) jog, at a slow pace	**2**
Moderate, (for example) walk, at a fast pace	**3**
Light, (for example) walk, at a medium pace	**4** 
Very light, (for example) walk, at a slow pace or not able to walk	**5** 

Feelings

During the past 2 weeks…
How much have you been bothered by emotional problems such as feeling anxious, depressed, irritable or downhearted and sad?

Not at all	1
Slightly	 2
Moderately	 3
Quite a bit	4
Extremely	5

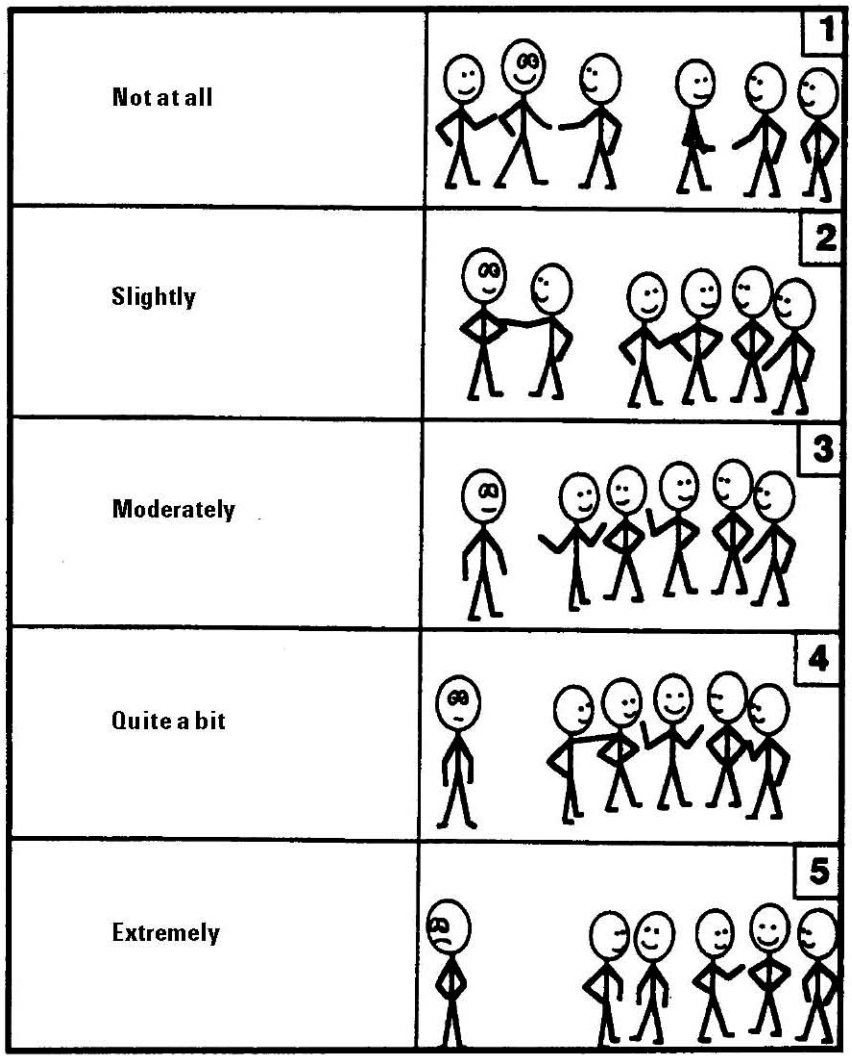
Daily activities

During the past 2 weeks…
How much difficulty have you had doing your usual activities or tasks, both inside and outside the house because of your physical and emotional health?

No difficulty at all	1
A little bit of difficulty	2
Some difficulty	3
Much difficulty	4
Could not do	5

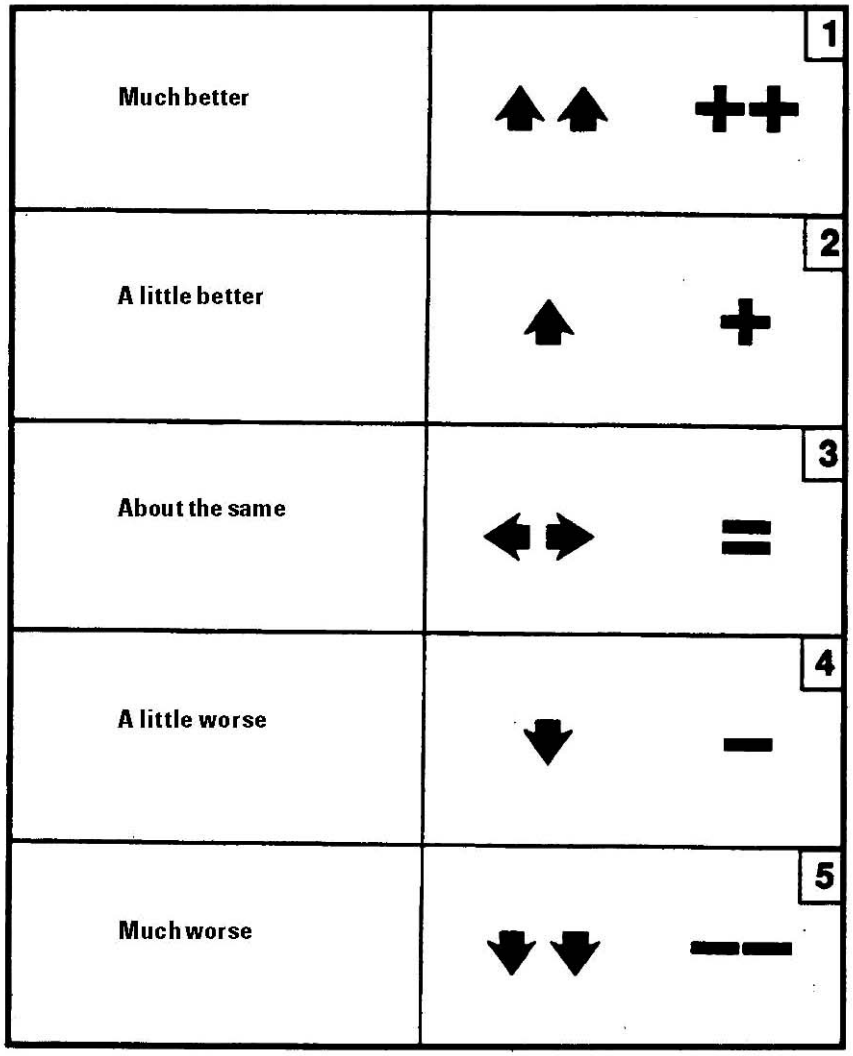
Social activities

During the past 2 weeks...
Has your physical an emotional health limited your social acivities with family, friends, neigbours or groups?



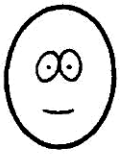
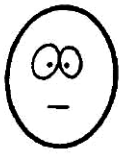
Change in health

How would you rate your overall health now compared to 2 weeks ago?



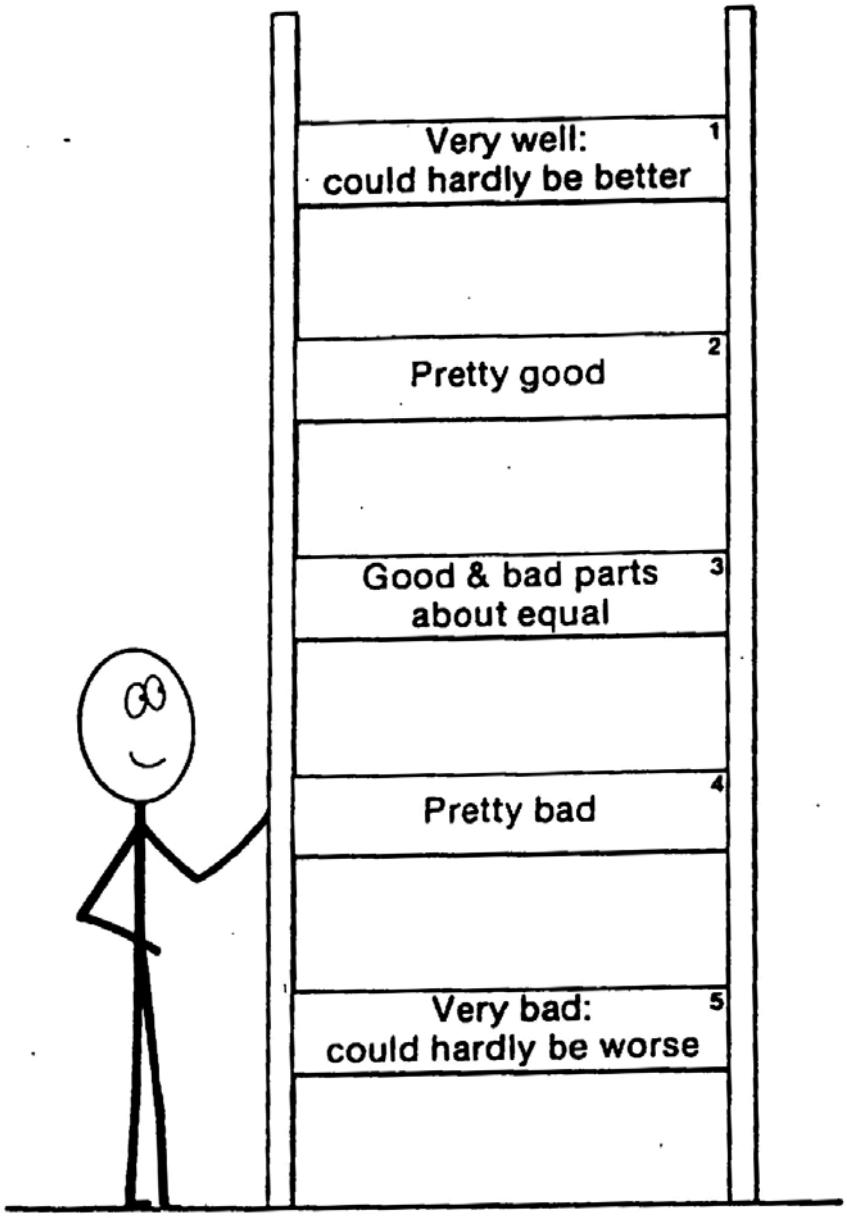
Overall health

During the past 2 weeks...
How would you rate your health in general?

Excellent	1
Very good	2 
Good	3 
Fair	4
Poor	5

QUALITY OF LIFE

How have things been going for you during the past 2 weeks?



PAIN

During the past 2 weeks . . .
How much bodily pain have you generally had ?

No pain		1
Very mild pain		2
Mild pain		3
Moderate pain		4
Severe pain		5

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COPE

The COPE Inventory was developed to assess a broad range of coping responses, several of which had an explicit basis in theory. The inventory includes some responses that are expected to be dysfunctional, as well as some that are expected to be functional

The items have been used in at least 3 formats. One is a "dispositional" or trait-like version in which respondents report the extent to which they usually do the things listed, when they are stressed. A second is a time-limited version in which respondents indicate the degree to which they actually did have each response during a particular period in the past. The third is a time-limited version in which respondents indicate the degree to which they have been having each response during a period up to the present.

The formats differ in their verb forms: the dispositional format is present tense, the situational-past format is past tense, the third format is present tense progressive (I am ...) or present perfect (I have been ...).

Abbreviated Name: COPE
Author(s): CS Carver, MF Scheier & JK Weintraub
Purpose: To assess a broad range of coping responses
Population: Adult
Type of Instrument: Coping
Mode of Administration: Self-administered

Rater:	Self-administered
Time required:	30 minutes
Response Options:	4-point Likert scale
Scoring:	Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 60 (complete version) and 28 (abbreviated version)
Original Language: English
Existing Translations : Spanish

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Contact for information and permission to use:

Charles S. Carver, Ph.D.
Department of Psychology
University of Miami
P.O. Box 248185
Coral Gables, Florida 33124-2070 USA
Email: ccarver@miami.edu

Dimensions covered by the questionnaire :

- Positive reinterpretation and growth (4 items)
- Mental disengagement (4 items)
- Focus on and venting of emotions (4 items)
- Use of instrumental social support (4 items)
- Active coping (4 items)
- Denial (4 items)
- Religious coping (4 items)
- Humor (4 items)
- Behavioral disengagement (4 items)
- Restraint (4 items)
- Use of emotional social support (4 items)
- Substance use (4 items)
- Acceptance (4 items)
- Suppression of competing activities (4 items)
- Planning (4 items)

Key References:

1. Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: a theoretically based approach. J Pers Soc Psychol. 1989;56(2):267-83

We developed a multidimensional coping inventory to assess the different ways in which people respond to stress. Five scales (of four items each) measure conceptually distinct aspects of problem-focused coping (active coping, planning, suppression of competing activities, restraint coping, seeking of instrumental social support); five scales measure aspects of what might be viewed as emotional-focused coping (seeking of emotional social support, positive reinterpretation, acceptance, denial, turning to religion); and three scales measure coping responses that arguably are less useful (focus on and venting of emotions, behavioral disengagement, mental disengagement). Study 1 reports the development of scale items. Study 2 reports correlations between the various coping scales and several theoretically relevant personality measures in an effort to provide preliminary information about the inventory's convergent and discriminant validity. Study 3 uses the inventory to assess coping responses among a group of undergraduates who were attempting to cope with a specific stressful episode. This study also allowed an initial examination of associations between dispositional and situational coping tendencies.

2. Perczek R, Carver CS, Price AA et al. Coping, mood, and aspects of personality in Spanish translation and evidence of convergence with English versions. J Pers Assess 2000;74(1):63-87

Research on stress and its influence on health and well-being has flourished for several decades, examining as predictors such psychosocial variables as personality and coping. This work now often targets multiethnic samples. Because many potential participants lack facility in English, a need exists for translations of measures into other languages. We translated 6 instruments into Spanish and studied their characteristics. Of these, 3 were measures of personality qualities: the Life Orientation Test--Revised (Scheier, Carver, & Bridges, 1994), the Behavioral Inhibition/Behavioral Activation Scales (Carver & White, 1994), and the Measure of Body Apperception (Carver et al., 1998). The others were the Brief COPE (Carver, 1997), the Center for Epidemiological Studies--Depression Scale (Radloff, 1977), and an abbreviated version of the Profile of Mood States (McNair, Lorr, & Droppelman, 1971). Correlations between English and Spanish versions in bilingual samples were all above. 72, except for the COPE's Behavioral Disengagement scale. Alpha reliabilities of the Spanish versions were comparable to those of the English versions. Correlations among measures in a sample of cancer patients were similar across languages.

3. Carver CS. You want to measure coping but your protocol's too long: Consider the Brief COPE. International Journal of Behavioral Medicine 1997;4:92-100

Studies of coping in applied settings often confront the need to minimize time demands on participants. The problem of participant response burden is exacerbated further by the fact that these studies typically are designed to test multiple hypotheses with the same sample, a strategy that entails the use of many time-consuming measures. Such research would benefit from a brief measure of coping assessing several responses known to be relevant to effective and ineffective coping. This article presents such a brief form of a previously published measure called the COPE inventory (Carver, Scheier, & Weintraub, 1989), which has proven to be useful in health-related research. The Brief COPE omits two scales of the full COPE, reduces others to two items per scale, and adds one scale. Psychometric properties of the Brief COPE are reported, derived from a sample of adults participating in a study of the process of recovery after Hurricane Andrew.

Brief COPE

The items below are an abbreviated version of the COPE Inventory. We have used it in research with breast cancer patients, with a community sample recovering from Hurricane Andrew, and with other samples as well. At present, none of that work has been published, except for an article reporting the development of the Brief COPE, which includes information about factor structure and internal reliability from the hurricane sample (citation below).
We created the shorter item set partly because earlier patient samples became impatient at responding to the full instrument (both because of the length and redundancy of the full instrument and because of the overall time burden of the assessment protocol). In choosing which items to retain for this version (which has only 2 items per scale), we were guided by strong loadings from previous factor analyses, and by item clarity and meaningfulness to the patients in a previous study. In creating the reduced item set, we also "tuned" some of the scales somewhat (largely because some of the original scales had dual focuses) and omitted scales that had not appeared to be important among breast cancer patients. In this way the positive reinterpretation and growth scale became positive reframing (no growth); focus on and venting of emotions became venting (focusing was too tied to the experiencing of the emotion, and we decided it was venting we were really interested in); mental disengagement became self-distraction (with a slight expansion of mentioned means of self-distraction). We also added one scale that was not part of the original inventory--a 2-item measure of self-blame--because this response has been important in some earlier work.

You are welcome to use all scales of the Brief COPE, or to choose selected scales for use. Feel free as well to adapt the language for whatever time scale you are interested in.

Citation: Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. International Journal of Behavioral Medicine, 4, 92-100.

Following is the brief COPE as we are now administering it, with the instructional orientation for a presurgery interview (the first time the COPE is given in this particular study). Please feel free to adapt the instructions as needed for your application.

Scales are as follows:

Self-distraction, items 1 and 19
Active coping, items 2 and 7
Denial, items 3 and 8
Substance use, items 4 and 11
Use of emotional support, items 5 and 15
Use of instrumental support, items 10 and 23
Behavioral disengagement, items 6 and 16
Venting, items 9 and 21
Positive reframing, items 12 and 17
Planning, items 14 and 25
Humor, items 18 and 28
Acceptance, items 20 and 24
Religion, items 22 and 27
Self-blame, items 13 and 26

Brief COPE

These items deal with ways you've been coping with the stress in your life since you found out you were going to have to have this operation. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real.".
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

COPE (complete version)

The COPE Inventory was developed to assess a broad range of coping responses, several of which had an explicit basis in theory. The inventory includes some responses that are expected to be dysfunctional, as well as some that are expected to be functional. It also includes at least 2 pairs of polar-opposite tendencies. These were included because each scale is unipolar (the absence of this response does not imply the presence of its opposite), and because we think people engage in a wide range of coping during a given period, including both of each pair of opposites.
The items have been used in at least 3 formats. One is a "dispositional" or trait-like version in which respondents report the extent to which they usually do the things listed, when they are stressed. A second is a time-limited version in which respondents indicate the degree to which they actually did have each response during a particular period in the past. The third is a time-limited version in which respondents indicate the degree to which they have been having each response during a period up to the present. The formats differ in their verb forms: the dispositional format is present tense, the situational-past format is past tense, the third format is present tense progressive (I am ...) or present perfect (I have been ...).

You are welcome to use all scales of the COPE, or to choose selected scales for use. Feel free as well to adapt the language for whatever time scale you are interested in. Be sure to adapt the instructions for completion, as well as the items themselves.

An abbreviated version of the COPE has also been created, if you have time constraints or high response burden.

Citation: Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. Journal of Personality and Social Psychology, 56, 267-283.

The items below are the "dispositional" version of the COPE Inventory, as we have administered it. The items are followed by instructions regarding which items are summed for each scale.

Scales (sum items listed):

Positive reinterpretation and growth: 1, 29, 38, 59
Mental disengagement: 2, 16, 31, 43
Focus on and venting of emotions: 3, 17, 28, 46
Use of instrumental social support: 4, 14, 30, 45
Active coping: 5, 24, 47, 58
Denial: 6, 27, 40, 57
Religious coping: 7, 18, 48, 60
Humor: 8, 20, 36, 50
Behavioral disengagement: 9, 24, 37, 51
Restraint: 10, 22, 41, 49
Use of emotional social support: 11, 23, 34, 52
Substance use: 12, 26, 35, 53
Acceptance: 13, 21, 44, 54
Suppression of competing activities: 15, 33, 42, 55
Planning: 19, 32, 39, 56

COPE

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you generally do and feel, when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress.

Then respond to each of the following items by blackening one number on your answer sheet for each, using the response choices listed just below. Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer every item. There are no "right" or "wrong" answers, so choose the most accurate answer for YOU--not what you think "most people" would say or do. Indicate what YOU usually do when YOU experience a stressful event.

1 = I usually don't do this at all
2 = I usually do this a little bit
3 = I usually do this a medium amount
4 = I usually do this a lot

1. I try to grow as a person as a result of the experience.
2. I turn to work or other substitute activities to take my mind off things.
3. I get upset and let my emotions out.
4. I try to get advice from someone about what to do.
5. I concentrate my efforts on doing something about it.
6. I say to myself "this isn't real."
7. I put my trust in God.
8. I laugh about the situation.
9. I admit to myself that I can't deal with it, and quit trying.
10. I restrain myself from doing anything too quickly.

11. I discuss my feelings with someone.
12. I use alcohol or drugs to make myself feel better.
13. I get used to the idea that it happened.
14. I talk to someone to find out more about the situation.
15. I keep myself from getting distracted by other thoughts or activities.
16. I daydream about things other than this.
17. I get upset, and am really aware of it.
18. I seek God's help.
19. I make a plan of action.
20. I make jokes about it.

21. I accept that this has happened and that it can't be changed.
22. I hold off doing anything about it until the situation permits.
23. I try to get emotional support from friends or relatives.
24. I just give up trying to reach my goal.
25. I take additional action to try to get rid of the problem.
26. I try to lose myself for a while by drinking alcohol or taking drugs.
27. I refuse to believe that it has happened.
28. I let my feelings out.
29. I try to see it in a different light, to make it seem more positive.
30. I talk to someone who could do something concrete about the problem.

31. I sleep more than usual.
32. I try to come up with a strategy about what to do.

33. I focus on dealing with this problem, and if necessary let other things slide a little.
34. I get sympathy and understanding from someone.
35. I drink alcohol or take drugs, in order to think about it less.
36. I kid around about it.
37. I give up the attempt to get what I want.
38. I look for something good in what is happening.
39. I think about how I might best handle the problem.
40. I pretend that it hasn't really happened.

41. I make sure not to make matters worse by acting too soon.
42. I try hard to prevent other things from interfering with my efforts at dealing with this.
43. I go to movies or watch TV, to think about it less.
44. I accept the reality of the fact that it happened.
45. I ask people who have had similar experiences what they did.
46. I feel a lot of emotional distress and I find myself expressing those feelings a lot.
47. I take direct action to get around the problem.
48. I try to find comfort in my religion.
49. I force myself to wait for the right time to do something.
50. I make fun of the situation.

51. I reduce the amount of effort I'm putting into solving the problem.
52. I talk to someone about how I feel.
53. I use alcohol or drugs to help me get through it.
54. I learn to live with it.
55. I put aside other activities in order to concentrate on this.
56. I think hard about what steps to take.
57. I act as though it hasn't even happened.
58. I do what has to be done, one step at a time.
59. I learn something from the experience.
60. I pray more than usual.

DUKE HEALTH PROFILE

Originally conceived as a 63-item measure, DUKE has been pared down to 17 questions that profile six domains (physical, mental, social, general, perceived health, and self-esteem), and four dysfunction measures (anxiety, depression, pain and disability). The format is easy to fill out and scoring is simple.

Abbreviated Name: DUKE
Author(s): George R. Parkerson, Jr., MD, MPH
Purpose: To measure self-reported health-related quality of life and functional health status.
Population: Adult
Age Range : 18 to 96
Type of Instrument: Quality of life and Functional Health status
Mode of Administration:

Rater:	Self-/ Interviewer-administered
Time required:	5 minutes
Response Options:	Yes/No and 3-point Likert scale
Scoring:	Global score Scores by dimension Scores by items
Score Direction:	Higher scores show better QoL (for separate items, overall global score, and each of the 6 functional dimensions). Lower scores show better QoL (for each of the 5 dysfunctional dimensions).

Number of Items: 17
Original Language: English
Existing Translations : Afrikaans, Chinese, Dutch, French, German, Italian, Korean, Norwegian, Polish, Portuguese, Spanish, Swedish.

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Contact for information and permission to use:

Professor George R Parkerson, Jr., MD, MPH
Box 2914 Duke University Medical Center
Durham, North Carolina 27710, USA
Phone: (919)-681-3043
Fax: (919) 684-8675
Email: parke001@mc.duke.edu.

Dimensions covered by the questionnaire :

- Physical health (5 items)
- Mental health (5 items)
- Social health (5 items)
- General health (15 items)
- Perceived health (1 item)
- Self-esteem (5 items)
- Anxiety (6 items)
- Depression (5 items)
- Anxiety-Depression, or DUKE-AD (7 items)
- Pain (1 item)-Disability (1 item)
- Overall HRQOL (17 items)

Key References:

1. Parkerson GR Jr, Broadhead WE, Tse C-KJ. Quality of Life and Functional Health of Primary Care Patients. Journal of Clinical Epidemiology 1992;45(11):1303-1313.

Quality of life and functional health were measured cross-sectionally for 314 adult ambulatory primary care patients in a rural clinic and found to be much better for patients with low severity of illness who required no confinement to home because of health problems, than for patients with high severity of illness who required confinement. Severity of illness was the strongest predictor for patient-reported physical health function and for patient quality of life when assessed by the health provider. Confinement was the strongest predictor for patient quality of life when assessed by the patient. There was very little agreement between patient-assessed and provider-assessed quality of life. Family stress was the strongest predictor of function in terms of mental health, social health, general health, self-esteem, anxiety, and depression. These data suggest that clinicians should direct increased attention to patient-assessed quality of life, patient-reported functional health status, and psychosocial factors such as family stress in an effort to improve medical outcomes.

2. Parkerson GR Jr, Broadhead WE, Tse C-KJ. Development of the 17-Item Duke Health Profile. FamilyPractice, 1991;8(4):396-401.

The 17-item Duke Health Profile (DUKE) was developed as a refined version of the 63-item Duke-UNC Health Profile (DUHP) using a methodology based upon a balanced clinical and statistical rationale. The result is a brief, valid functional health measure with 10 scales that compares well with the MOS Short-form and the COOP Charts. In addition to the five constructs (ambulation, emotional symptoms, activities with friends or relatives, health perception, and pain) which are measured by all three of the instruments, the DUKE quantitates cognition, social self-esteem, confinement, and somatic symptoms other than pain.

3. Parkerson GR Jr, Broadhead WE, Tse C-KJ. Comparison of the Duke Health Profile and the MOS Short-form in Healthy Young Adults. Medical Care 1991;29(7):679-683.
4. Parkerson GR Jr, Broadhead WE, Tse, C-KJ. The Duke Health Profile, A 17-Item Measure of Health and Dysfunction. Medical Care 1990;28(11):1056-1072.

FORM A: FOR SELF-ADMINISTRATION BY THE RESPONDENT (revised 4-2000)

DUKE HEALTH PROFILE (The DUKE)

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Duke University Medical Center, Durham, N.C., U.S.A.

Date Today:_____ Name: _____ ID Number:_____

Date of Birth:_____ Female____ Male_____

INSTRUCTIONS: Here are some questions about your health and feelings. Please read each question carefully and check (√) your best answer. You should answer the questions in your own way. There are no right or wrong answers. (Please ignore the small scoring numbers next to each blank.)

		Yes, describes me exactly	Somewhat describes me	No, doesn't describe me at all
1.	I like who I am	12	11	10
2.	I am not an easy person to get along with	20	21	22
3.	I am basically a healthy person	32	31	30
4.	I give up too easily	40	41	42
5.	I have difficulty concentrating	50	51	52
6.	I am happy with my family relationships	62	61	60
7.	I am comfortable being around people	72	71	70

TODAY would you have any physical trouble or difficulty:

		None	Some	A Lot
8.	Walking up a flight of stairs	82	81	80
9.	Running the length of a football field	92	91	90

DURING THE PAST WEEK: How much trouble have you had with:

		None	Some	A Lot
10.	Sleeping	102	101	100
11.	Hurting or aching in any part of your body	112	111	110
12.	Getting tired easily	122	121	120
13.	Feeling depressed or sad	132	131	130
14.	Nervousness	142	141	140

DURING THE PAST WEEK: How often did you:

		None	Some	A Lot
15.	Socialize with other people (talk or visit with friends or relatives)	150	151	152
16.	Take part in social, religious, or recreation activities (meetings, church, movies, sports, parties)	160	161	162

DURING THE PAST WEEK: How often did you:

		None	1-4 Days	5-7 Days
17.	Stay in your home, a nursing home, or hospital because of sickness, injury, or other health problem	172	171	170

MANUAL SCORING FOR THE DUKE HEALTH PROFILE

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Duke University Medical Center, Durham, N.C., U.S.A.

Item	Raw Score*
8 =	_____
9 =	_____
10 =	_____
11 =	_____
12 =	_____
Sum =	_____ x 10 =

PHYSICAL HEALTH SCORE ☐

Item	Raw Score*
1 =	_____
4 =	_____
5 =	_____
13 =	_____
14 =	_____
Sum =	_____ x 10 =

MENTAL HEALTH SCORE ☐

Item	Raw Score*
2 =	_____
6 =	_____
7 =	_____
15 =	_____
16 =	_____
Sum =	_____ x 10 =

SOCIAL HEALTH SCORE ☐

GENERAL HEALTH SCORE

Physical Health score = _____
Mental Health score = _____
Social Health score = _____
Sum = _____ ÷ 3 =

☐

PERCEIVED HEALTH SCORE

Item	Raw Score*
3 =	_____ x 50 =

☐

Item	Raw Score*
1 =	_____
2 =	_____
4 =	_____
6 =	_____
7 =	_____
Sum =	_____ x 10 =

SELF-ESTEEM SCORE ☐

To calculate the scores in this column the raw scores must be revised as follows:
If 0, change to 2; if 2, change to 0; if 1, no change.

Item	Raw Score*	Revised
2 =	_____	_____
5 =	_____	_____
7 =	_____	_____
10 =	_____	_____
12 =	_____	_____
14 =	_____	_____
	Sum =	_____ x 8.333 =

ANXIETY SCORE ☐

Item	Raw Score*	Revised
4 =	_____	_____
5 =	_____	_____
10 =	_____	_____
12 =	_____	_____
13 =	_____	_____
	Sum =	_____ x 10 =

DEPRESSION SCORE ☐

Item	Raw Score*	Revised
4 =	_____	_____
5 =	_____	_____
7 =	_____	_____
10 =	_____	_____
12 =	_____	_____
13 =	_____	_____
14 =	_____	_____
	Sum =	_____ x 7.143 =

ANXIETY-DEPRESSION (DUKE-AD) SCORE ☐

PAIN SCORE

Item	Raw Score*	Revised
11 =	_____	_____ x 50 =

☐

DISABILITY SCORE

Item	Raw Score*	Revised
17 =	_____	_____ x 50 =

☐

* Raw Score = last digit of the numeral adjacent to the blank checked by the respondent for each item. For example, if the second blank is checked for item 10 (blank numeral = 101), then the raw score is "1", because 1 is the last digit of 101.

Final Score is calculated from the raw scores as shown and entered into the box for each scale. For physical health, mental health, social health, general health, self-esteem, and perceived health, 100 indicates the best health status, and 0 indicates the worst health status. For anxiety, depression, anxiety-depression, pain, and disability, 100 indicates the worst health status and 0 indicates the best health status.

Missing Values: If one or more responses is missing within one of the eleven scales, a score cannot be calculated for that particular scale.

DUKE SEVERITY OF ILLNESS CHECKLIST

Duke Severity of Illness Checklist (DUSOI) has been developed by George R. Parkerson. Original instruments have been published in English. The DUSOI is an objective measure of physical health status. The purpose of this instrument is to measure a person's illness severity. The DUSOI takes into account prognosis, medical complication level and patient symptoms for all current medical diagnoses.

Abbreviated Name: DUSOI
Author(s): George R. Parkerson, Jr., MD, MPH
Purpose: To measure a person's illness severity
Population: Adult
Age Range : 18 to 96 years
Type of Instrument: Symptoms
Mode of Administration:

Rater:	Proxy-administered
Time required:	1 to 2 minutes for medical providers 2 to 3 minutes for medical record auditors
Response Options:	Yes/No and 3-point Likert scale
Scoring:	Global score Scores by dimension Scores by items
Score Direction:	Lower scores show better QoL
Weighting:	Yes

Number of Items: 4 for each diagnosis
Original Language: English
Existing Translations : Dutch, French, German and Norwegian

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Duke University Medical Center, Durham, NC, USA

Contact for information and permission to use:

Professor George R Parkerson, Jr., MD, MPH
Box 2914 Duke University Medical Center
Durham, North Carolina 27710, USA
Phone: (919) 681-3043
Fax: (919)-684-8675
Email: parke001@mc.duke.edu

Dimensions covered by the questionnaire :

- Symptoms (5 items)
- Complications (5 items)
- Prognosis (5 items)
- Treatability (5 items)
- Overall severity (20 items)

Key References:

1. Parkerson GR Jr, Hammond WE, Yarnall KSH. Feasibility and Potential Clinical Usefulness of a Computerized Severity of Illness Measure. Archives of Family Medicine 1994;3(11):968-973

Objective: To assess the feasibility and potential clinical usefulness of the computerized Duke Severity of Illness Checklist (DUSOI). Design: Cross-sectional study of patients whose severity of illness was measured with the DUSOI. Providers assessed the clinical usefulness of the DUSOI and recorded the length of time required for rating severity. Auditors rated severity using progress note information. Demographic and financial data from clinic records were also obtained. Setting: University-based family practice clinic with 64,621 annual visits. Patients: Convenience sample of ambulatory patients. Main Outcome Measures: Clinical usefulness and time required to rate severity. Results: For 117 patients (63.3% female; mean age, 46.3 years), the mean charge was $105.38, the mean number of health problems was 2.0, the mean overall provider DUSOI score was 33.7, and the mean auditor DUSOI score was 34.0 (scale = 0 to 100). There was excellent agreement between provider and auditor DUSOI scores (intraclass correlation coefficient, .77). Providers required 1.1 minutes to record severity; the principal auditor required 1.6 minutes. Providers found the DUSOI potentially useful in 30.3% of patients. Usefulness was greater in women (38.2% of women vs 18.2% of men), older patients (mean age, 54.5 years in useful group vs 41.9 in nonuseful group), and sicker patients (mean DUSOI score, 55.1 vs 25.9). The DUSOI was more clinically useful in patients with health problems such as type II diabetes mellitus (75.0%) than in those with problems such as tobacco use (25.0%). Higher charges correlated with a higher number of health problems and with female gender but not with severity scores. Conclusions: The computerized DUSOI is feasible for all patients and is potentially useful for women, older, and sicker patients.

2. Parkerson GR Jr, Broadhead WE, Tse CK. The Duke Severity of Illness Checklist (DUSOI) for measurement of severity and comorbidity. J Clin Epidemiol 1993;46:379-93.

The Duke Severity of Illness Checklist (DUSOI) was evaluated on 414 primary care adult patients using data collected both by medical providers at the time of the patient visit and later by a chart auditor. Severity scores for individual diagnoses were determined by summing the ratings for four non-disease-specific parameters: symptom level, complications, prognosis without treatment, and expected response to treatment. Mean diagnosis severity scores (scale 0-100) among the 21 most prevalent diagnoses varied from a low of 13.9 for menopausal syndrome to a high of 43.0 for sprains and strains. An overall severity score was calculated by combining diagnosis severity scores and giving highest weights to the most severe diagnoses. Provider-generated overall severity scores (mean = 43.3) and auditor-generated overall severity scores (mean = 38.9) were significantly correlated (coefficient of agreement = 0.59, $p < 0.0001$). Diagnoses varied in their individual contribution to the overall severity score, from 8.9% for lipid disorder to 90.0% for sprains and strains. Separate comorbidity severity scores were calculated to measure the severity of all of each patient's health problems except the diagnosis under study. For example, patients with menopausal syndrome had co-existing health problems which generated a high mean comorbidity severity score of 43.2, while patients with sprains and strains had a low mean comorbidity score of 4.7. The DUSOI Checklist can be used in the clinical setting by both providers and auditors to produce quantitative severity scores (by diagnosis, overall, and for comorbidity) which are based entirely upon clinical judgment. This method should be useful in controlling for severity of illness in clinical studies and indicating the outcome of medical care in terms of reduction in severity of illness following medical interventions.

3. Parkerson GR Jr, Broadhead WE, Tse C-KJ. Quality of Life and Functional Health of Primary Care Patients. Journal of Clinical Epidemiology 1992;45(11):1303-1313.

Quality of life and functional health were measured cross-sectionally for 314 adult ambulatory primary care patients in a rural clinic and found to be much better for patients with low severity of illness who required no confinement to home because of health problems, than for patients with high severity of illness who required confinement. Severity of illness was the strongest predictor for patient-reported physical health function and for patient quality of life when assessed by the health provider. Confinement was the strongest predictor for patient quality of life when assessed by the patient. There was very little agreement between patient-assessed and provider-assessed quality of life. Family stress was the strongest predictor of function in terms of mental health, social health, general health, self-esteem, anxiety, and depression. These data suggest that clinicians should direct increased attention to patient-assessed quality of life, patient-reported functional health status, and psychosocial factors such as family stress in an effort to improve medical outcomes.

4. Parkerson GR Jr, Michener JL, Wu LR, Finch JN, Muhlbaier LH, Magruder-Habib K, Kertesz JW, Clapp-Channing N, Morrow DS, Chen A L-T, Jokerst E. Associations Among Family Support, Family Stress, and Personal Functional Health Status. Journal of Clinical Epidemiology 1989;42(3):217-229.

The self-reported family support and stress of 249 ambulatory adult patients, aged 18-49 years, were studied relative to their self-reported functional health. Support from family members was found to be related positively with emotional function. Stress from family members was associated negatively with symptom status, physical function, and emotional function. Patients' severity of illness was related negatively to their symptom status, physical function, and social function, but not to their emotional function. During the study a new self-report instrument, the Duke Social Support and Stress Scale (DUSOCS), was developed to measure family and non-family support and stress. Also, a new chart audit methodology, the Duke Severity of Illness Scale (DUSOI), was designed to assess severity in the ambulatory setting. Reliability and validity of the DUSOCS and the DUSOI were supported. The importance of the patient's perception of health and its family determinants is emphasized.

ID#_____

DUKE SEVERITY OF ILLNESS CHECKLIST (DUSOI)*

Provider: _____ Date of Encounter: _____

If Audit, Date: _____ Auditor: _____ Patient=s Name:_____

Health Problems	Severity Scores (Enter Codes 0-4)**			
	Symptoms	Complications	Prognosis	Treatability
1. _____				
2. _____				
3. _____				
4. _____				
5. _____				
6. _____				
7. _____				
8. _____				
9. _____				
10. _____				

** SEVERITY CODING CRITERIA

	None	Questionable	Mild	Moderate	Major
1. Symptoms (past week):	0	1	2	3	4
2. Complications (past week):	0	1	2	3	4
	Disability				
3. Prognosis (next 6 months,	None	Mild	Moderate	Major	Threat to Life
without treatment):	0	1	2	3	4
	Need for Treatment			Expected Response to Treatment	
	No	Questionable	IF YES JJ	Good	Questionable	Poor
4. Treatability:	0	1		2	3	4

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DUKE SOCIAL SUPPORT AND STRESS SCALE

The Duke Social Support and Stres Scale (DUSOCS) is an existing 24-item scale designed to measure social support, social stress, family support, and family stress. The DUSOCS has six subscales: family support, non-family support, total support, family stress, non-family stress, and total stres.

Abbreviated Name: DUSOCS
Author(s): George R. Parkerson, Jr., MD, MPH
Purpose: To assess the frequency and severity with wich symptoms of depression are experienced in the general population
Population: Adult
Age Range : 18 to 96 years
Type of Instrument: Social functioning
Mode of Administration:

Rater:	Self-/ Interviewer-administered
Time required:	3 - 5 minutes
Response Options:	Yes/No and 3-point Likert scale
Scoring:	Global score Scores by dimension Scores by items
Score Direction:	Lower scores show better QoL

Number of Items: 24
Original Language: English
Existing Translations : Portuguese

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Duke University Medical Center, Durham, NC, USA

Contact for information and permission to use:

Professor George R Parkerson, Jr., MD, MPH
Box 2914 Duke University Medical Center
Durham, North Carolina 27710, USA
Phone: (919)-681-3043
Fax: (919) 684-8675
Email: parke001@mc.duke.edu.

Dimensions covered by the questionnaire :

- Family support (8 items)
- Non-family support (6 items)
- Social support (12 items)
- Family stress (8 items)
- Non-family stress (6 items)
- Social stress (12 items)

Key References:

1. Parkerson GR Jr, Michener JL, Wu LR, Finch JN, Muhlbaier LH, Magruder-Habib K, Kertesz JW, Clapp-Channing N, Morrow DS, Chen A L-T, Jokerst E. Associations Among Family Support, Family Stress, and Personal Functional Health Status. Journal of Clinical Epidemiology 1989;42(3):217-229.

The self-reported family support and stress of 249 ambulatory adult patients, aged 18-49 years, were studied relative to their self-reported functional health. Support from family members was found to be related positively with emotional function. Stress from family members was associated negatively with symptom status, physical function, and emotional function. Patients' severity of illness was related negatively to their symptom status, physical function, and social function, but not to their emotional function. During the study a new self-report instrument, the Duke Social Support and Stress Scale (DUSOCS), was developed to measure family and non-family support and stress. Also, a new chart audit methodology, the Duke Severity of Illness Scale (DUSOI), was designed to assess severity in the ambulatory setting. Reliability and validity of the DUSOCS and the DUSOI were supported. The importance of the patient's perception of health and its family determinants is emphasized.

2. Parkerson GR Jr, Michener JL, Wu LR, Finch JN, Broadhead WE, Muhlbaier LH, Magruder-Habib K, Helms MJ, Kertesz JW, Clapp-Channing N, Jokerst E. The Effect of a Telephone Family Assessment Intervention on the Functional Health of Patients with Elevated Family Stress. Medical Care 1989; 27(7):680-693.

A randomized trial of a telephone family assessment intervention was conducted during a 2.5 month period on 224 ambulatory primary care patients, aged 18-49 years, who were selected according to self-report of elevated family stress levels. Family physicians conducted telephone interviews to collect information from patients on their supportive and stressful family members. The working hypothesis was that this process would lead to reduction in the patient's family stress and to improvement in family support and personal health status. Patients reported that the intervention caused them to think about their family support and helped them to feel better. Comparison of family factor and functional health scores before and after intervention also indicated a limited beneficial effect, but only for a small subset of black patients. These results suggest that the telephone family assessment alone is inadequate as an intervention and should be strengthened to include professional assistance to patients for the family problems that are identified by the assessment.

3. Parkerson GR Jr, Broadhead WE, Tse C-KJ. Validation of the Duke Social Support and Stress Scale Using the Duke Health Profile. Family Medicine 1991;23(5):357-360.

The Duke Social Support and Stress Scale (DUSOCS) was validated in 249 adult family practice patients using the Family Strengths, the Family Inventory of Life Events, and the Duke Health Profile (DUKE) as comparison instruments. Validity was supported in that the DUSOCS family support measure had the clinically expected positive associations with DUKE health measures (regression coefficients of +7.4 to +18.7) and negative associations with DUKE anxiety and depression measures (-2.0 to -17.2). DUSOCS family stress had negative associations with the health measures (-11.6 to -34.5) and positive associations with anxiety and depression (+18.9 to +32.1). Family and non-family stress contributed more than severity of illness to elevated levels of anxiety and depression and lowered levels of mental health, social health, and self-esteem, while these same stresses contributed only half as much as severity of illness to lowered physical health.

FORM A: FOR SELF-ADMINISTRATION BY THE RESPONDENT (revised 1-99)

DUKE SOCIAL SUPPORT AND STRESS SCALE (DUSOCS)

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Date Today:_____ Name:_____ ID#:_____

Date of Birth:_____ Female__ Male__

PAGE 1: SUPPORT

I. People Who Give Personal Support

[A supportive person is one who is helpful, who will listen to you, or who will back you up when you are in trouble.]

INSTRUCTIONS: Please look at the following list and decide how much each person (or group of persons) is supportive for you at this time in your life. Check (T) your answer.

How supportive are these people now:	None	Some	A Lot	There is No Such Person
1. Your wife, husband, or significant other person.....	_____	_____	_____	_____
2. Your children or grandchildren	_____	_____	_____	_____
3. Your parents or grandparents.....	_____	_____	_____	_____
4. Your brothers or sisters	_____	_____	_____	_____
5. Your other blood relatives.....	_____	_____	_____	_____
6. Your relatives by marriage (for example: in-laws, ex-wife ex-husband).....	_____	_____	_____	_____
7. Your neighbors.....	_____	_____	_____	_____
8. Your co-workers.....	_____	_____	_____	_____
9. Your church members	_____	_____	_____	_____
10. Your other friends	_____	_____	_____	_____

	Yes	No
11. Do you have one particular person whom you trust and to whom you can go with personal difficulties?.....	_____	_____

12. If you answered "yes", which of the above types of person is he or she? (for example: child, parent, neighbor)_____

PAGE 2: STRESS (DUSOCS FORM A)

II. People Who Cause Personal Stress

[A person who stresses you is one who causes problems for you or makes your life more difficult.]

INSTRUCTIONS: Please look at the following list and decide how much each person (or group of persons) is a stress for you at this time in your life. Check (T) your answer.

How stressed do you feel by these people now:	None	Some	A Lot	There is No Such Person
1. Your wife, husband, or significant other person	_____	_____	_____	_____
2. Your children or grandchildren	_____	_____	_____	_____
3. Your parents or grandparents	_____	_____	_____	_____
4. Your brothers or sisters	_____	_____	_____	_____
5. Your other blood relatives	_____	_____	_____	_____
6. Your relatives by marriage (for example: in-laws, ex-wife ex-husband)	_____	_____	_____	_____
7. Your neighbors	_____	_____	_____	_____
8. Your co-workers	_____	_____	_____	_____
9. Your church members	_____	_____	_____	_____
10. Your other friends	_____	_____	_____	_____

	Yes	No
11. Is there one particular person who is causing you the most personal stress now?	_____	_____

12. If you answered "yes", which of the above types of person is he or she? (for example: child, parent, neighbor) _____

SCORING FOR THE DUKE SOCIAL SUPPORT AND STRESS SCALE

Scoring is done either manually as described below, or by computer as shown in Appendix F.

DUSOCS Social Support

Support Step 1: Assign the following raw scores for each check mark made by the respondent:

"None" = 0 "Yes" = 2
"Some" = 1 "No" = 0
"A Lot" = 2 "There is No Such Person" = 0

Rules for missing values: If all items in the entire "support" section are left blank, then all are considered to be "missing values" and no support scores can be generated. However, if at least one item is checked in the support section, then all the blanks are scored "0" and the check or checks are scored "0" to "2" as noted above.

Support Step 2: Calculate the score for **DUSOCS Family Support**

a. Sum the raw scores for the six categories of family members under Section IA.

b. If the "special supportive person" in Section IC is a family member, add the raw score for "yes" (i.e., 2) to the sum of IA. If not a family member, add the raw score for "no" (i.e., 0).

c. Divide by 14 and multiply by 100 to obtain the Family Support Score on a scale of 0 to 100.

Example: For the patient shown in Figure 16, the score for Family Support is calculated as follows:

a. Sum the raw scores for the six categories of family members under Section IA.

Type of person		Raw Score
1. Your wife, husband, or significant other person	=	2
2. Your children or grandchildren	=	0
3. Your parents or grandparents	=	2
4. Your brothers or sisters	=	1
5. Your other blood relatives	=	1
6. Your relatives by marriage	=	2
Sum	=	**8**

b. If the "special supportive person" in Section IC is a family member, add the raw score for "yes" (i.e., 2) to the sum of IA. If not a family member, add the raw score for "no" (i.e., 0). to the sum of IA.

Special supportive person = wife
Because "wife" is a family member, add the raw score of 2: **8 + 2 = 10**

c. Divide by 14 and multiply by 100 to obtain the Family Support Score on a scale of 0 to 100.

10 ÷ 14 = 0.714
0.714 X 100 = **71.4 = DUSOCS Family Support Score**

Support Step 3: Calculate the score for **DUSOCS Non-Family Support.**
a. Sum the raw scores for the four categories of non-family members under Section IB.
b. If the "special supportive person" in Section IC is a non-family member, add the raw score for "yes" (i.e., 2) to the sum of IB. If not a non-family member, add the raw score for "no" (i.e., 0) to the sum of IB.
c. Divide by 10 and multiply by 100 to obtain the Non-Family Support Score on a scale of 0 to 100.
Example: For the patient shown in Figure 16, the score for Non-Family Support is calculated as follows:
a. Sum the raw scores for the four categories of non-family members under Section IB.

Type of Person		Raw Score
Your neighbors	=	1
Your co-workers	=	2
Your church members	=	0
Your other friends	=	1
Sum	=	**4**

b. If the "special supportive person" in Section IC is a non-family member, add the raw score for "yes" (i.e., 2) to the sum of IB. If not a non-family member, add the raw score for "no" (i.e., 0) to the sum of IB.

Because the special supportive person (i.e., wife) is not a non-family member,
the raw score of 0 is added: **4 + 0 = 4**

c. Divide by 10 and multiply by 100 to obtain the Non-Family Support Score on a scale of 0 to 100: 4 ÷ 10 = 0.40
0.40 x 100 = **40.0 = DUSOCS Non-Family Support Score**

Support Step 4: Calculate the score for **DUSOCS Social Support**
a. Sum the raw scores for Sections IA, IB, and IC.
b. Divide by 22 and multiply by 100 to obtain the Social Support Score on a scale of 0 to 100.

Example: For the patient shown in Figure 16, the score for Social Support is calculated as follows:
a. Sum the raw scores for Sections IA, IB, and IC: 8 + 4 + 2 = **14**

b. Divide by 22 and multiply by 100 to obtain the Social Support score on a scale of 0 to 100: 14 ÷ 22 = 0.636

O.636 x 100 = **63.6 = DUSOCS Social Support score**

DUSOCS Social Stress

Stress Step 1: Assign the following raw scores for each check mark made by the respondent:

"None" = 0	"Yes" = 2
"Some" = 1	"No" = 0
"A Lot" = 2	"There is No Such Person" = 0

Rules for missing values: If all items in the entire "stress" section are left blank, then all are considered to be "missing values" and no stress scores can be generated. However, if at least one item is checked in the stress section, then all the blanks are scored "0" and the check or checks are scored "0" to "2" as noted above.

Stress Step 2: Calculate the score for **DUSOCS Family Stress.**

a. Sum the raw scores for the six categories of family members under Section IIA.
b. If the "most stressful person" in Section IIC is a family member, add the raw score for "yes" (i.e., 2) to the sum of IIA. If not a family member, add the raw score for "no" (i.e., 0).
c. Divide by 14 and multiply by 100 to obtain the Family Stress Score on a scale of 0 to 100.

Example: For the patient shown in Figure 17, the score for Family Stress is calculated as follows:

a. Sum the raw scores for the six categories of family members under Section IIA.

Type of person		Raw Score
1. Your wife, husband, or significant other person	=	1
2. Your children or grandchildren	=	0
3. Your parents or grandparents	=	1
4. Your brothers or sisters	=	2
5. Your other blood relatives	=	1
6. Your relatives by marriage	=	1
Sum	=	**6**

b. If the "most stressful person" in Section IIC is a family member, add the raw score for "yes" (i.e., 2) to the sum of IIA. If not a family member, add the raw score for "no" (i.e., 0). to the sum of IIA.

Most stressful person = brother
Because "brother" is a family member, add the raw score of 2: **6 + 2 = 8**

c. Divide by 14 and multiply by 100 to obtain the Family Stress Score on a scale of 0 to 100.

8 ÷ 14 = 0.571
0.571 X 100 = **57.1 = DUSOCS Family Stress Score**

Stress Step 3: Calculate the score for **DUSOCS Non-Family Stress.**
a. Sum the raw scores for the four categories of non-family members under Section IIB.
b. If the "most stressful person" in Section IIC is a non-family member, add the raw score for "yes" (i.e., 2) to the sum of IIB. If not a non-family member, add the raw score for "no" (i.e., 0) to the sum of IIB.
c. Divide by 10 and multiply by 100 to obtain the Non-Family Stress Score on a scale of 0 to 100.
Example: For the patient shown in Figure 17, the score for Non-Family Stress is calculated as follows:
a. Sum the raw scores for the four categories of non-family members under Section IIB.

Type of Person		Raw Score
Your neighbors	=	1
Your co-workers	=	1
Your church members	=	0
Your other friends	=	0
Sum	=	**2**

b. If the "most stressful person" in Section IIC is a non-family member, add the raw score for "yes" (i.e., 2) to the sum of IIB. If not a non-family member, add the raw score for "no" (i.e., 0) to the sum of IIB.

Because the most stressful person (i.e.,brother) is not a non-family member, the raw score of 0 is added: **2 + 0 = 2**
c. Divide by 10 and multiply by 100 to obtain the Non-Family Stress Score on a scale of 0 to 100: 2 ÷ 10 = 0.20
0.20 x 100 = **20.0 = DUSOCS Non-Family Stress Score**

Stress Step 4: Calculate the score for **DUSOCS Social Stress**
a. Sum the raw scores for Sections IIA, IIB, and IIC.
b. Divide by 22 and multiply by 100 to obtain the Social Stress Score on a scale of 0 to 100.

Example: For the patient shown in Figure 17, the score for Social Stress is

calculated as follows:

a. Sum the raw scores for Sections IIA, IIB, and IIC: 6 + 2 + 2 = **10**

b. Divide by 22 and multiply by 100 to obtain the Social Stress score on a scale of 0 to 100: 10 ÷ 22 = 0.455

O.455 x 100 = **45.5 = DUSOCS Social Stress score**

In summary, the DUSOCS scores for the sample patient shown in Figure 16 and Figure 17 are as follows:

1. Family Support score = 71.4
2. Non-Family Support score = 40.0
3. Social Support score = 63.6
4. Family Stress score = 57.1
5. Non-Family Stress score = 20.0
6. Social Stress score = 45.5

FORM A: FOR SELF-ADMINISTRATION BY THE RESPONDENT (revised 1-99)

DUKE SOCIAL SUPPORT AND STRESS SCALE (DUSOCS)

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Date Today: *9-3-96* Name: *Jim Williams* ID#: *001*
Date of Birth: *7-2-51* Female__ Male *√*

PAGE 1: SUPPORT

I. People Who Give Personal Support

[A supportive person is one who is helpful, who will listen to you, or who will back you up when you are in trouble.]

INSTRUCTIONS: Please look at the following list and decide how much each person (or group of persons) is supportive for you at this time in your life. Check (✓) your answer.

How supportive are these people now:	None	Some	A Lot	There is No Such Person
1. Your wife, husband, or significant other person			√	
2. Your children or grandchildren				√
3. Your parents or grandparents			√	
4. Your brothers or sisters		√		
5. Your other blood relatives		√		
6. Your relatives by marriage (for example: in-laws, ex-wife ex-husband)			√	
7. Your neighbors		√		
8. Your co-workers			√	
9. Your church members				√
10. Your other friends		√		

	Yes	No
11. Do you have one particular person whom you trust and to whom you can go with personal difficulties?	√	

12. If you answered "yes", which of the above types of person is he or she? (for example: child, parent, neighbor) *Wife*

PAGE 2: STRESS (DUSOCS FORM A)

II. People Who Cause Personal Stress

[A person who stresses you is one who causes problems for you or makes your life more difficult.]

INSTRUCTIONS: Please look at the following list and decide how much each person (or group of persons) is a stress for you at this time in your life. Check (✓) your answer.

How stressed do you feel by these people now:	None	Some	A Lot	There is No Such Person
1. Your wife, husband, or significant other person		✓		
2. Your children or grandchildren				✓
3. Your parents or grandparents		✓		
4. Your brothers or sisters			✓	
5. Your other blood relatives		✓		
6. Your relatives by marriage (for example: in-laws, ex-wife ex-husband)		✓		
7. Your neighbors		✓		
8. Your co-workers		✓		
9. Your church members				✓
10. Your other friends	✓			

	Yes	No
11. Is there one particular person who is causing you the most personal stress now?	✓	

12. If you answered "yes", which of the above types of person is he or she? (for example: child, parent, neighbor) *Brother*

EUROQOL-5D

EQ-5D is a standardised instrument for use as a measure of health outcome. Applicable to a wide range of health conditions and treatments, it provides a simple descriptive profile and a single index value for health status that can be used in the clinical and economic evaluation of health care as well as population health surveys. EQ-5D has been specially designed to complement other quality of life measures such as the SF-36, NHP, SIP or disease-specific measures. The current 3-level, 5-dimensional format of the EQ-5D will remain unchanged for the immediate future.

EQ-5D is designed for self-completion by respondents and is ideally suited for use in postal surveys, in clinics and face to face interviews. It is cognitively simple, taking only a few minutes to complete. Instructions to respondents are included in the questionnaire.

Although EQ-5D was intended for self-completion, the EuroQol Group recognizes that this is not always appropriate. Guidelines for observer, telephone and proxy use are in preparation. Please contact the EuroQol Business Management for more information.

Abbreviated Name: EQ-5D
Author(s): The EuroQol Group
Purpose: To assess health outcome from a wide variety of interventions on a common scale, for purposes of evaluation, allocation and monitoring
Population: Adult
Age Range : +12 years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-administered
Time required:	8 minutes
Response Options:	3-point Likert scale - Visual Analog Scale (VAS)
Scoring:	Global score
Score Direction:	Higher scores show better QoL
Weighting:	Yes

Number of Items: 5
Original Language: The EQ-5D was initially developed simultaneously in Dutch, English, Finnish, Norwegian and Swedish.
Existing Translations : Afrikaans, Argentinean, German, Belgian French, Bulgarian, Catalan, Croatian, Czech, Danish, French, Greek, Hungarian, Italian, Japanese, Polish, Portuguese, Russian, Turkish, Armenian, Basque, Chinese, Chilean, Estonian, Filipino, Hebrew, Icelandic, Indonesian, Korean, Latvian, Lithuanian, Malay, Romanian, Sesotho (South Africa), Shona (Zimbabwe), Slovakian, Singapore, Slovenian, Thai, Tongan (New Zealand), Xhosa (South Africa), Zulu (South Africa).

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Contact for information and permission to use:

Dr Frank de Charro
EuroQol Business Manager
PO BOX 4443
3006 AK Rotterdam The Netherlands
Phone: +31 10 408 1545
Fax: +31 10 452 5303
E-mail: fdecharro@compuserve.com

Dimensions covered by the questionnaire :

- Mobility (3 levels)
- Self-care (3 levels)
- Usual activities (3 levels)
- Pain / Discomfort (3 levels)
- Anxiety / Depression (3 levels)

Key References:

1. EuroQol--a new facility for the measurement of health-related quality of life. The EuroQol Group. Health Policy. 1990 Dec;16(3):199-208

In the course of developing a standardised, non-disease-specific instrument for describing and valuing health states, the EuroQol Group conducted postal surveys in England, The Netherlands and Sweden which indicate a striking similarity in the relative valuations attached to 14 different health states. The data were collected using a visual analogue scale similar to a thermometer. The EuroQol instrument is intended to complement other quality-of-life measures and to facilitate the collection of a common data set for reference purposes. Others interested in participating in the extension of this work are invited to contact the EuroQol Group.

2. Brooks R. EuroQol: the current state of play. Health Policy 1996;37(1):53-72

The EuroQol Group first met in 1987 to test the feasibility of jointly developing a standardised non-disease-specific instrument for describing and valuing health-related quality of life. From the outset the Group has been multi-country, multi-centre, and multi-disciplinary. The EuroQol instrument is intended to complement other forms of quality of life measures, and it has been purposefully developed to generate a cardinal index of health, thus giving it considerable potential for use in economic evaluation. Considerable effort has been invested by the Group in the development and valuation aspects of health status measurement. Earlier work was reported upon in 1990; this paper is a second 'corporate' effort detailing subsequent developments. The concepts underlying the EuroQol framework are explored with particular reference to the generic nature of the instrument. The valuation task is reviewed and some evidence on the methodological requirements for measurement is presented. A number of special issues of considerable interest and concern to the Group are discussed: the modelling of data, the duration of health states and the problems surrounding the state 'dead'. An outline of some of the applications of the EuroQol instrument is presented and a brief commentary on the Group's ongoing programme of work concludes the paper.

3. Kind P, Dolan P, Gudex C, Williams A. Variations in population health status: results from a United kingdom national questionnaire survey. BMJ 1998;316(7133):736-741

Objective: To measure the health of a representative sample of the population of the United Kingdom by using the EuroQoL EQ-5D questionnaire. Design: Stratified random sample representative of the general population aged 18 and over and living in the community. SETTING: United Kingdom. Subjects: 3395 people resident in the United Kingdom. Main Outcome Measures: Average values for mobility, self care, usual activities, pain or discomfort, and anxiety or depression. Results: One in three respondents reported problems with pain or discomfort. There were differences in the perception of health according to the respondent's age, social class, education, housing tenure, economic position, and smoking behaviour. Conclusions: The EQ-5D questionnaire is a practical way of measuring the health of a population and of detecting differences in subgroups of the population.

4. De Charro F, Rabin R. EQ-5D from the EuroQol group: an update. QOL Newsletter, 2000; 25

Most quality of life researchers are probably familiar with EQ-5D developed by the EuroQol Group. Currently, EQ-5D defines health in terms of 5 dimensions – mobility, self care, usual activities, pain/discomfort and anxiety/depression. Each dimension is divided into 3 levels, i.e. no problem/some or moderate problems/ extreme problems. A respondent's health state is defined by combining one level from each of the 5 dimensions. A total of 243 possible health states can be defined in this way. This information can be used to generate a simple health profile or converted into a single summary index by applying scores from a set of general population preference weights. EQ-5D also captures a self-rating of health status on a 20 cm vertical visual analogue scale, anchored at 100 (best imaginable health state) at the top and 0 (worst imaginable health state) at the bottom.
The EuroQol Group originally consisted of a network of international multi-disciplinary researchers from Europe, but today includes members from the USA, Canada and Japan. The Group has a formal Board of Management and a growing Business Office in the Netherlands. EQ-5D has proved to be a robust, easy to use instrument with a proven performance in a wide variety of clinical settings. Currently, EQ-5D is being used by eight out of the first ten of the top fifty pharmaceutical companies listed in the annual report of Pharma Business (November/December 1999). EQ-5D is one of only three such instruments recommended by the Washington Panel on Cost Effectiveness in Medicine and is now available in 30 approved translations/ cultural adaptations, while 16 others have been completed and are awaiting approval. Latest versions produced in cooperation with Mapi Research Institute include those for Russia, Guatemala, Costa Rica and Colombia. Translation work outside Europe and North America is increasing with the recent production of a Taiwanese Chinese version and a Shona version for Zimbabwe.

5. Rabin R, de Charro F. EQ-5D: a measure of health status from the EuroQol Group. The Finnish Medical Society Duodecim, Ann Med 2001;33:337-343

Established in 1987, the EuroQol Group initially comprised a network of international, multilingual and multidisciplinary researchers from seven centres in Finland, the Netherlands, Norway, Sweden and the UK. Nowadays, the Group comprises researchers from Canada, Denmark, Germany, Greece, Japan, New Zealand, Slovenia, Spain, the USA and Zimbabwe. The process of shared development and local experimentation resulted in EQ-5D, a generic measure of health status that provides a simple descriptive profile and a single index value that can be used in the clinical and economic evaluation of health care and in population health surveys. Currently, EQ-5D is being widely used in different countries by clinical researchers in a variety of clinical areas. EQ-5D is also being used by eight out of the first 10 of the top 50 pharmaceutical companies listed in the annual report of Pharma Business (November/December 1999). Furthermore, EQ-5D is one of the handful of measures recommended for use in cost-effectiveness analyses by the Washington Panel on Cost Effectiveness in Health and Medicine. EQ-5D has now been translated into most major languages with the EuroQol Group closely monitoring the process.

THE EUROQOL GROUP

In l987 an international, multidisciplinary group of researchers from seven centres in England, Finland, the Netherlands, Norway and Sweden began to collaborate. The aim was and is the development of a standardised non-disease specific instrument for describing and valuing health-related quality of life.

The ensuing process of shared development, local experimentation and extensive discussion of the complex issues involved, resulted in the EuroQol instrument, a multidimensional measure of health-related quality of life, capable of being expressed as a single index value.

The EuroQol instrument has been in the public domain since l990. The EuroQol was initially developed as a six-dimensional instrument but was modified in October l991 to produce the current standard format comprising five dimensions. This version is called the EQ-5D and is now used widely by an increasing number of clinical researchers, health policy and decision makers and the pharmaceutical industry. A user guide has been produced to support its use.

The original seven research groups have since been joined by two research groups from Spain as well as researchers from Germany, Greece, Canada and the US.

The EuroQol was initially developed simultaneously in Dutch, English, Finnish, Norwegian and Swedish. Since then the following versions have been officially approved by the EuroQol Group: Catalan, Croatian, Czech, Danish, French, German, Italian, Polish, Québécoise, Spanish and Turkish. Hebrew, Japanese and Portuguese translations are in progress. In addition, lay panel assessment has been carried out on the EQ-5D English version to determine its appropriateness for Irish, Australian and US populations.

The EuroQol Group has now been formally constituted as an Association with an elected Executive Committee. A EuroQol Foundation has also been formally constituted and registered in the Netherlands and is governed on behalf of the Group by a small Board of Management.

THE EQ-5D

The EQ-5D has been designed as an international, standardised, generic instrument for describing and valuing health-related quality of life. The instrument has been specially designed to *complement* other forms of quality of life measures.
The main characteristics of the EQ-5D are:

- it is a simple generic measure, which includes only the basic domains common to generic health status measures.
- it has the minimum number of questions for each domain.
- the instrument produces an overall single number, or an 'index' for health status.
- the EQ-5D can be used to collect data in a self-administered form and is suitable for use in postal surveys.

The EQ-5D has four distinct purposes:

First, page 2 provides a simple method for obtaining an accurate *self-description* of current health-related quality of life. Second, page 3 offers a simple method for generating *a self-rating* of current health-related quality of life. This part of the EQ-5D is called the *descriptive part* of the instrument and these pages are the most frequently used in clinical research and clinical trials. The third purpose of the EQ-5D is to provide a technique for valuing health states. The *valuation* part of the instrument consists of pages 4 - 7 and has been used to value heath states in population studies in the following countries:

- Finland
- Netherlands
- Norway
- Sweden
- UK

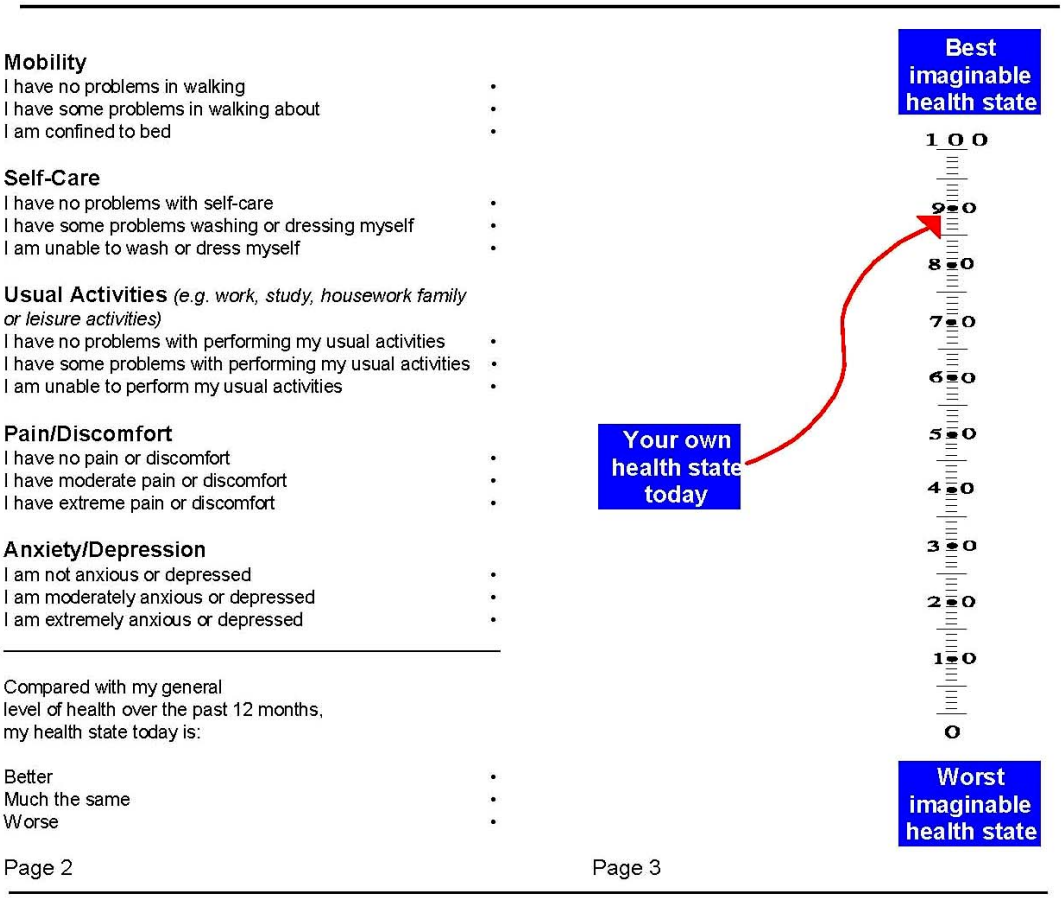
and more recently in other countries:

- Spain
- Germany
- US
- Greece

Fourth, pages 8 and 9 of the instrument contain a series of questions designed to elicit background information.

THE DESCRIPTIVE PART OF THE EUROQOL EQ-5D PAGES 2 AND 3

Pages 2 and 3 of the EQ-5D, together with the background information from pages 8/9 if required, are now often referred to as the descriptive part of the instrument. Applicable to a wide range of health conditions and treatments, pages 2 and 3 provide a concise descriptive profile and a single index value that can be used for both clinical and economic evaluations of health care. The descriptive part of the EQ-5D has been specially designed to *complement* other health-related quality of life measures.



THE CLASSIFICATION: PAGE 2

Dimensions

The dimensions were chosen following a detailed review of existing available health status measures.

In selecting the descriptors, the Group was anxious to incorporate as many as possible of the dimensions frequently covered in other instruments. In its initial form, the instrument classified health-related quality of life according

to scores on six dimensions i.e. mobility, self-care, main activity, social relationships, pain and mood.

Analysis of the separate contribution of each dimension revealed that social relationships played little part in determining health state valuations. The number of dimensions was consequently reduced from six to five, with social relationships being incorporated within the 'usual activities' dimension.

Levels

Each dimension comprises three levels, generating a total of 243 theoretically possible health states. The format offers a balanced structure for each dimension, giving equal weight to each level in the resulting composite health states.

The three levels reflect increasing degrees of difficulty, i.e:

- level 1: no problem
- level 2: some or moderate problems
- level 3: unable, or extreme problems

Change in health status

Finally on page 2, respondents are asked to indicate their health state today compared with their general level of health over the past 12 months by ticking (marking) the most appropriate box.

Instructions for using page 2

The respondent is asked to indicate his/ her health state by ticking (or crossing) the box against the most appropriate state-ment in each dimension. This decision results in a one-digit number expressing the level selected for that dimension. The digits for five dimensions can be combined in a five-digit number, which describes the respondent's health state.

Coding

The responses are straightforward to code and record.

There is <u>one</u> response for each dimension, such that:

level 1 is coded as a '1'
level 2 is coded as a '2'
level 3 is coded as a '3'

A respondent's own health state can therefore be described in terms of a five-digit number, for example, state 11111 indicates no problem on any of the five dimensions, while state 21121 indicates some problem with mobility and moderate pain but no problem with self-care, usual activities or anxiety or depression.

THE THERMOMETER:PAGE 3

Page 3 of the EQ-5D offers a simple method for obtaining a self-rating of current health-related quality of life by means of a scale (like a thermometer). The EQ-5D “thermometer” is a vertical 20 cm visual analogue scale, with endpoints of 100 (best imaginable health state) at the top and 0 (worst imaginable health state) at the bottom.

While page 2 enables the respondent to classify his/her health state, health state *scores* do not arise from these descriptions but instead from the visual analogue scale on page 3. This page should be used in conjunction with the five-digit classification on page 2 to build an accurate profile of the respondent's health status.

Instructions for using page 3

The respondent is asked to indicate the score for his/her own health state by drawing a line across the thermometer.

Coding

A three-digit number between 000 and 100 is read off the thermometer, from the exact point where the line crosses the scale, for example, 046 or 098.

USING THE RESPONSES FROM PAGES 2 AND 3

Pages 2 and 3 of the EQ-5D instrument provide a simple, but effective, measure of health-related quality of life.

The descriptive data generated from page 2 may be used to profile respondents, either through time for a particular respondent or cross-sectionally, comparing outcomes for different respondents.

The self-rated information derived from page 3 may then be used to analyse changes in the health status of individuals or groups of individuals over time.

The responses can be used in the following ways:

- The five-digit codes describing health states can be used as profiles.
- The five-digit codes describing health states can be converted to a weighted index using population values.
- the thermometer scores can be used as an individual measure of overall self-rated health.

Each of these provides a different indication of the distribution of health states across a population or, if repeated, of the change over time in a respondent's health state, for use in the monitoring and evaluation of health outcomes.

THE VALUATION PART: PAGES 4 - 7

The valuation part of the EQ-5D questionnaire is printed on pages 4 - 7. It was designed to elicit valuations for health states other than the state which the respondent is currently in. It differs from the descriptive part where respondents are asked about their own health state today. The valuation part concerns health states which are not the health state of the respondent. These pages are therefore rarely used in clinical research and are only for those researchers who wish to go beyond data collection on health-related quality of life and elicit valuations as well.

The valuations are derived using the same visual analogue scale (VAS) method as has been used in the descriptive part.

All the EQ-5D postal surveys have used this VAS method, collecting data on a "common core" set of 14 states (13 EQ-5D states plus "unconscious"). These states are displayed on pages 5 and 6 of the instrument. Two states 11111 and 33333 are repeated on both pages to act as common reference points. On page 7, respondents are asked to return to pages 5 and 6 and to draw a line to indicate the position of the state “dead” in comparison to the other states.

Over the past few years, the EuroQol Group has been engaged in several projects which have aimed at eliciting values from general population samples in Finland, Germany, Greece, Netherlands, Spain, Sweden, UK and US. More recent research has concentrated on statistical modeling to generate values for all the 243 theoretically possible health states defined by the EQ-5D.

The Business Management of the EuroQol Group acts as an intermediary supplying information on the background to the research in the various countries. However to date, the research carried out as part of the MVH Project at York University UK has been underpinned by the most elaborate research effort. EuroQol members at York have access to several large population databases in which the EQ-5D has been fielded together with patient data covering a number of different clinical areas. Information can be requested from Paul Kind at the Centre for Health Economics, University of York, UK (Tel: +44 1904 433653, Fax: +44 1904 433644, E-mail: pk1@york.ac.uk)

Data analysis

An “off the shelf” software package such as SPSS, SAS or BMDP may be used to analyse EuroQol data.

PAGES 8/9 OF THE EQ-5D: DEMOGRAPHIC QUESTIONS

The final section, (pages 8/9 of the full version, page 4 of the descriptive part), contains a series of questions designed to elicit background information on occupation/activity, age, sex, education and qualifications, experience of illness, whether smoker or not and whether or not the respondent has worked in the health or social services.

EQ-5D CONDITIONS FOR USAGE

The EQ-5D questionnaire may be used without cost provided that the research is not being undertaken for commercial purposes, e.g. the testing of a new product by the Pharmaceutical Industry. More information on the Group's policy in these instances can be obtained from the EuroQol Business Management.

For non-commercial academic and clinical use, the EQ-5D is freely available, however the Group does require that only official language versions of the instrument are used and that users register their project. Free use of the EQ-5D also implies that users are willing to share their knowledge with the Group regarding the application of the EQ-5D as well as information which adds to the methodological knowledge of the instrument, e.g., issues surrounding validity and reliability. The Group is also particularly interested in demographic data, comparative data (where the EQ-5D has been used alongside other instruments) and valuation data as well as data relating to the EQ-5D classification and the EQ-5D VAS rating scale.

Further information

A full user guide is available on request from the EuroQol Business Management in Rotterdam, Netherlands, at a nominal charge of DFL 60 (within NL) and DFL 80 (outside NL). The Business Management can also provide other documentation, e.g.

- the descriptive part of the instrument and the full version.
- different language versions
- EuroQol references
- details of clinical studies using the EQ-5D

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dr Frank de Charro
EuroQol Business Management
Centre for Health Policy and Law,
Erasmus University Rotterdam W L4-057
PO Box 1738,
3000 DR Rotterdam
Netherlands
Tel: +31 10 4082364
Fax:+31 10 4525303
E-mail:deCharro@GBR.FRG.EUR.NL

By placing a check in <u>one</u> box for items please indicate which statement best describes your own health today.

Mobility

1 ☐ I have no problems in walking about
2 ☐ I have some problems in walking about
3 ☐ I am confined to bed

Self-Care

1 ☐ I have no problems with self-care
2 ☐ I have some problems washing or dressing myself
3 ☐ I am unable to wash or dress myself

Usual Activities ***(e.g., work, study, housework, family or leisure activities)***

1 ☐ I have no problems with performing my usual activities
2 ☐ I have some problems with performing my usual activities
3 ☐ I am unable to perform my usual activities

Pain/Discomfort

1 ☐ I have no pain or discomfort
2 ☐ I have moderate pain or discomfort
3 ☐ I have extreme pain or discomfort

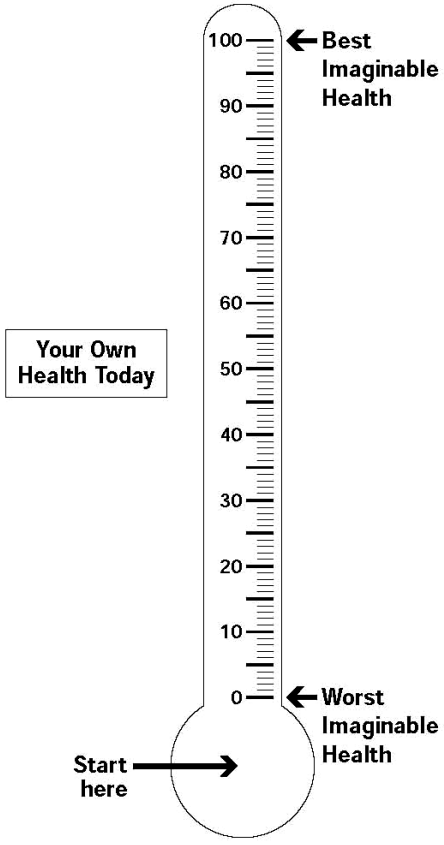
Anxiety/Depression

1 ☐ I am not anxious or depressed
2 ☐ I am moderately anxious or depressed
3 ☐ I am extremely anxious or depressed

Rating of Your Own Health Today

To help you say how good or bad your own health is today, we have drawn a scale (rather like a thermometer) on which the best imaginable health is marked by 100 and the worst imaginable is marked by 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the circle at the bottom of thermometer below to whichever point on the thermometer indicates how good or bad your own health is today.



FAMILY SYSTEM TEST

The Family System Test (FAST) was developed at Stanford and the University of Zurich for use with both individuals and families. It is a figural technique, derived from clinical practice, for representing emotional bonds (cohesion) and hierarchical structures in the family or similar social systems. The FAST, which can be used quantitatively or qualitatively, is based on the structural-systemic theory of families. It is assumed that healthy families have a balanced relationship structure (cohesive and with a balanced hierarchy), clear generation borders, and a flexible organization.

The FAST can be used as an individual or group test in research and clinical practice for: analysis of family structure; diagnosis of biopsychosocial problems; planning and evaluation of preventive and therapeutic interventions.

The FAST is very economical compared with other instruments which provide similar information. Another advantage of the FAST lies in its ability to trigger a process of reflection on family relations among respondents, thus facilitating diagnosis and therapy. A first evaluation is possible right after completion of the representations. For example, it is possible to determine structural characteristics such as clarity of generational boundaries without any prior calculations. A review of the follow-up interviews and the spontaneous comments of the family members permits ad hoc individual and family-oriented systemic hypotheses.

Test materials include a board and various schematic figures. Takes only 5-10 minutes for individuals, 10-30 minutes for groups. Language independent and highly effective.

Abbreviated Name: FAST
Author(s): Thomas M Gehring
Purpose: To assess family cohesion and hierarchy in typical, ideal and conflict constellations
Population: 6 and over
Type of Instrument: Psychosocial/psychological
Mode of Administration:

Rater:	Self-administered (Individual or Group)
Time required:	Individual test: 5 to 10 minutes; group test: 10 to 30 minutes
Response Options:	Figures with blocks
Scoring:	Global score
	Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: Board with 81 squares
Original Language: German
Existing Translations: Czech, Dutch, English, Finnish, French, Japanese, Spanish

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Contact for information and permission to use:

Thomas M. Gehring
Switzerland
E-Mail: tmgehring@bluewin.ch

Dimensions covered by the questionnaire :

- Cohesion and hierarchy in the family and its subsystems
- Quality of generational boundaries
- Flexibility of family structures

Key References:

1. Gehring, T.M. The Family System Test (FAST): Preliminary Manual (in German). NAPS-3.1984.
2. Gehring, T.M. & Wyler, I.L. Family System Test (FAST): A three-dimensional approach to investigate family relationships. Child Psychiatry and Human Development, 1986;16, 235-248.
3. Gehring, T.M., Debry, M. & Smith, P.K. The Family System Test (FAST): Theory and Application. London and Philadelphia: Routledge, 2001.
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5. Gehring, T.M. Familiensystemtest (FAST). Göttingen: Beltz, 1998 (2. erweiterte Auflage).
6. Gehring, T.M. & Hatta, T. Family System Test (Japanese Manual). Osaka: Union Press, 1997.
7. Gehring, T.M. Gezinssyteemtest (GEST). Handleiding. Lisse: Swets & Zeitlinger, 1995.
8. Gehring, T.M. & Debry, M. L'évaluation du Système Familial: Le FAST. Braine-Le-Château: Editions ATM, 1995.

FAST Test Case Example

Referral

Gabriel (age 19) is referred by his father to therapy for frequent drug consumption (cannabis).

Anamnesis

The family consists of the parents, the patient, who is socially well integrated and an average high school student, and his two-year older sister, who attends college in another city. The mother, a trained seamstress, works part-time in the father's consulting business. The father, an economist, comes from a poor and alcoholic family, and is becoming increasingly worried that his son's drug consumption will prevent him from finishing school. Gabriel, like his mother, feels that he is in control of his drug abuse and that it does not interfere with school performance. Both stress that the many points of disagreement between the parents have now shifted primarily to the issue of the children's future.

FAST representation

As the family sets up the group representation, a heated discussion ensues between the parents about child rearing issues. Gabriel (his sister is not present) treats his father with little respect and disqualifies him often. He also tends to align himself with the mother who in turn reproaches the father repeatedly. The typical family relations are portrayed as having a labile-balanced structure. Significant features are the relative centrifugality of the father and the hierarchy reversal (P - C2). In the follow-up interview the father maintains that he feels closer to the mother than the representation shows and expresses surprise that mother and son should perceive relations differently than he does. On the other hand, there are no differences of opinion regarding the structure of hierarchy.

Interpretation

The unclear generational boundaries and the problems in communication manifested in the FAST are seen as resulting from conflicts surrounding the approach of Gabriel's leaving home and problems in redefining the parental and marital relationship. This interpretation is supported by the information that the daughter (who is an occasional cannabis user, as well) was also frequently at the center of parental conflicts until she left home for college. The father's fears that she would turn into an addict proved unfounded. There appear to be many protective factors in Gabriel's favor resulting from his well-developed sense of autonomy. Therefore the risk of subsequent psychosocial disorders is thought to be minimal.

Problem-solving process

The father who initially proposed indiviudal sessions for Gabriel is now, like the mother, willing to participate in several family and parental sessions. Gabriel has little motivation to participate in family sessions.

In the course of therapy Gabriel and his parents redefine the rules that guide their living together. Although Gabriel consumed cannabis several times after a self-imposed period of abstinence, the relationship to his father is more relaxed. The mother decides to stop work in the father's consulting business and takes up her profession as a seamstress again. At the same time the number of arguments between the parents regarding their own relationship increases. Both feel, however, that they can solve these marital problems themselves without therapeutic support.

Evaluation of therapy

For an evaluation of therapy the FAST is administered again to the parents and son together. While setting up the family representation the parents begin a constructive discussion. No longer is the focus on child-raising issues but rather on the future course of their marital relationship. Unlike the first time, Gabriel remains in the background and does not attempt to disqualify his father. The typical family relations are portrayed as having now a balanced structure. Based on the relational structure depicted in the FAST at the start of therapy we see that perception of cohesion at the family level and between the parents is nearly unchanged. Relations between the parents, however, have become more egalitarian due to a perceived increase in the father's power. Generational boundaries are more clearly defined due to hierarchical parent-son relations (no hierarchy reversal or egalitarian relationships) and less cohesion between mother and son. Another indication for stronger generational boundaries is the direction in which the figures are facing. The represented transformations of the interpersonal structures reflect a positive individual and family development. Gabriel is about to complete high school and plans to begin college.

Follow-up

In a follow-up interview two years later all family members agree that their relationships are continuing to improve. Since Gabriel moved out of the house, the marital relationship of the parents has become more satisfactory for both. Gabriel completed an internship in a drug therapy center and has begun studying psychology at the local university.

FERRANS AND POWERS QUALITY OF LIFE INDEX

The Quality of Life Index (QLI) was developed by Ferrans and Powers to measure quality of life in terms of satisfaction with life. Quality of life is defined by Ferrans as "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her". The QLI measures both satisfaction and importance of various aspects of life. Importance ratings are used to weight the satisfaction responses, so that scores reflect the respondents' satisfaction with the aspects of life they value. Items that are rated as more important have a greater impact on scores than those of lesser importance. The instrument consists of two parts: the first measures satisfaction with various aspects of life and the second measures importance of those same aspects. Scores are calculated for quality of life overall and in four domains: health and functioning, psychological/ spiritual, social and economic, and family.

A number of versions of the QLI have been developed for use with various disorders and the general population, and have been reported in more than 100 published studies. A common set of items forms the basis for all versions, and items pertinent to each disorder have been added to create the illness-specific versions. Scores for all versions range from 0 - 30, which facilitates comparisons of findings across different versions. General population data are available for interpretive purposes.

Abbreviated Name: QLI
Author(s): Carol E. Ferrans and M.J Powers
Purpose: To measure quality of life in terms of satisfaction with life
Population: Adult
Type of Instrument: Quality of Life, Satisfaction
Mode of Administration:

Rater:	Self--administered
Time required:	10 minutes
Response Options:	Likert scale
Scoring:	Global score
	Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: Generic version: 66
Original Language: English
Existing Translations : French, Hungarian, Japanese, Korean, Mandarin Chinese, Norwegian, Polish, Portuguese, Romanian, Russian, Spanish, Swedish, Thai

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Contact for information and permission to use:

Carol Estwing Ferrans
PhD, RN, FAAN
Associate Professor
Department of Medical-Surgical Nursing (M/C 802)
College of Nursing
University of Illinois at Chicago
845 South Damen Avenue, 7th Floor, Room 746
Chicago, Illinois 60612-7350 USA
Fax: (312)-996-4979
E-mail: CFerrans@uic.edu

Dimensions covered by the questionnaire :

- Health and Functioning
- Psychological / Spiritual
- Social and Economic
- Family

Key References:

1. Ferrans CE. Development of a Conceptual Model of Quality of Life. Scholarly Inquiry for Nursing Practice: An International Journal 1996;10(3):293-304

Quality of life is a critically important concept for health care that has been developed predominantly in the past three decades. Conceptual clarity is extremely important, because differences in meaning can lead to profound differences in outcomes for research, clinical practice, and allocation of health care resources. This paper describes the development of the Ferrans conceptual model of quality of life. The model was developed based on the adoption of an individualistic ideology, which recognizes that quality of life depends on the unique experience of life for each person. Individuals are the only proper judge of their quality of life, because people differ in what they value. Consistent with this ideology, quality of life was defined in terms of satisfaction with the aspects of life that are important to the individual. The model was developed using qualitative methodology. Factor analysis of patient data was used to cluster related elements into domains of quality of life. The resulting model identifies four domains of quality of life: health and functioning, psychological/spiritual, social and economic, and family. Subsequent cross-cultural work with African Americans and Mexican Americans has provided evidence that the elements of the model appropriately reflect quality of life for segments of the population not sampled in the original work. The Ferrans and Powers Quality of Life Index was developed based on this model.

2. Ferrans CE, Powers MJ. Psychometric assessment of the Quality of Life Index. Research in Nursing and Health, 1992; 15: 29-38

The purpose of this study was to examine the psychometric properties of the Quality of Life Index (QLI) (Ferrans & Powers, 1985a). The sample consisted of 349 patients selected randomly from the adult, in-unit hemodialysis patient population of Illinois. Factor analysis was used to examine the underlying factor structure. A four-factors solution best fit the data, indicating that there were four dimensions underlying the QLI: health and functioning, socioeconomic, psychological/spiritual, and family. Factor analysis of the four primary factors revealed one higher order factor, representing quality of life. Construct validity also was supported by the contrasted groups approach. As predicted, it was found that those who had higher incomes had significantly higher quality of life scores on the social and economic subscale. Support for convergent validity was provided by a strong correlation (r = .77) between scores from the QLI and an assessment of life satisfaction. Findings supported the internal consistency reliability of the entire QLI (alpha = .93) and the four subscales (alphas = .87, .82, .90, .77).

3. Ferrans CE. Development of a quality of life index for patients with cancer. Oncology Nursing Forum, 1990;17(3): 15-19

This study developed an instrument to measure the quality of life (QOL) of patients with cancer that would account for individual values, as well as satisfaction. The sample consisted of patients with breast cancer (n = 111) listed in the tumor registry of a major hospital. Ferrans and Power's Quality of Life Index (QLI) was modified based on an extensive review of the oncology literature, which supported content validity. The findings supported the internal consistency reliability of the entire QLI (alpha = 0.95) and of the four subscales: health and functioning, socioeconomic, psychological/spiritual, and family (alphas = 0.90, 0.84, 0.93, and 0.66, respectively). Support for concurrent validity was provided by a strong correlation (r = 0.80) between the QLI and a measure of satisfaction with life. Support for construct validity was provided by significantly higher mean QOL scores for subjects who had less pain, less depression, and were coping better with stress, using the known group technique. The positive results obtained from this assessment and the fact that many patients can complete the QLI independently are important variables to consider when health professionals are selecting instruments for research and practice.

4. Ferrans C, Powers M. Quality of Life Index: Development and psychometric properties. Advances in Nursing Science, 1985; 8: 15-24

The purpose of the study on which this article is based was to assess the validity and reliability of an instrument designed to measure quality of life. Sixty-four items applicable to both healthy subjects and dialysis patients were tested with graduate students (n = 88); six items relative to dialysis were added, and the instrument was administered to dialysis patients (n = 37). Items were based on literature review, which supported content validity. Correlations between the instrument and an overall satisfaction with life question of 0.75 (graduate students) and 0.65 (dialysis patients) supported criterion-related validity. Support for reliability was provided by test-retest correlations of 0.87 (graduate students) and 0.81 (dialysis patients) and Cronbach's alphas of 0.93 (graduate students) and 0.90 (dialysis patients).

Reliability and Validity of the Ferrans and Powers Quality of Life Index (QLI)

Reliability

Internal Consistency Reliability. Internal consistency reliability for the QLI (total scale) was supported by Cronbach's alphas ranging from .84 to .98 across 20 studies (Table 1). Cronbach's alphas for the four subscales have been published in 11 studies, which have provided support for internal consistency of the subscales (Table 2). Alphas ranged from .70 to .93 for the health and functioning subscale, from .73 to .89 for the social and economic subscale, and from .80 to .93 for the psychological/spiritual subscale. For the family subscale, alphas were acceptably high in 10 studies, ranging from .63 to .92.

Temporal (Stability) Reliability. For the total scale, support for temporal reliability was provided by test-retest correlations of .87 with a two-week interval and .81 with a one-month interval (Ferrans & Powers, 1985) and by correlations of .78 with a three to four-week interval (Rustoen et al., 1999b). Temporal reliability also was supported by test-retest correlations with a two-week interval for all five scores: overall quality of life (r = .79), health and functioning (r = .72), social and economic (r = .68), psychological/spiritual (r = .76), and family (r = .69) (Dougherty et al., 1998).

Validity

Content Validity. Content validity of the QLI was supported by the fact that items were based both on an extensive literature review of issues related to quality of life and on the reports of patients regarding the quality of their lives (Ferrans & Powers, 1985). Support for content validity also was provided by an acceptably high rating using the Content Validity Index (Oleson, 1990).

Construct Validity. Convergent validity of the QLI was supported by strong correlations between the overall (total) QLI score and Campbell, Converse, and Rodgers' (1976) measure of life satisfaction (r = .61, .65, .75, .77, .80, .83, .93) (Bliley & Ferrans, 1993; Ferrans & Powers, 1985; Ferrans & Powers, 1992; Anderson & Ferrans, 1997; Ferrans, 1990).

Further evidence for construct validity was provided by factor analysis. Factor analysis revealed four dimensions underlying the QLI: health and functioning, social and economic, psychological/spiritual, and family. The factor analytic solution explained 91% of the total variance. Factor analysis of the four primary factors revealed one higher order factor, which represented quality of life (Ferrans & Powers, 1992).

Construct validity also was supported using the contrasted groups approach. Subjects were divided into groups on the basis of self-reported levels of pain, depression, and success in coping with stress. Subjects who had less pain, less depression, or who were coping better with stress had significantly higher overall (total) QLI scores (Ferrans, 1990). The contrasted groups approach also was used to assess the construct validity of the social and economic subscale. It was found that those who had higher incomes had significantly higher quality of life scores on the social and economic subscale (Ferrans & Powers, 1992).

Sensitivity to Change

Sixteen intervention studies have been published in which QLI scores were found to be sensitive enough to detect a change in quality of life. The QLI scores changed significantly over time, when compared before and after an intervention in all 15 studies (Table 3).

Table 1. Internal Consistency Reliability of the Ferrans and Powers Quality of Life Index (QLI): Total Scale

Population	Alpha	Study
Cancer		
Breast cancer patients		
Before treatment	.93	Hughes, 1993
After treatment (8 weeks)	.96	
Breast cancer survivors	.95	Ferrans, 1990
Melanoma patients	.95	Cowan et al., 1992
Newly diagnosed patients	.93, .95	Rustoen et al., 1999a; 1999b
Cardiac		
Angina pectoris (stable) patients	.93	Dougherty et al., 1998
Angiogram patients	.92	Delunas & Potempa, 1999
Angioplasty patients		
Before PTCA	.86	Bliley & Ferrans, 1993
After PTCA (4-6 weeks)	.96	
Angioplasty and bypass surgery patients	.98	Papadantonaki et al., 1994
Arrythmias (life-threatening)	.98	Carroll et al., 1999
Cardiac rehabilitation	.92	Deshotels et al., 1995
End Stage Renal Disease		
Hemodialysis and CAPD patients	.90	Ferrans & Powers, 1985
Hemodialysis patients	.93	Ferrans & Powers, 1992
HIV Positive/AIDS		
HIV+	.89	Nunes et al., 1995
HIV+	.84	Mellors et al., 1997
Other Illness Groups		
Chronic fatigue syndrome	.93	Anderson & Ferrans, 1997
Multiple sclerosis patients	.87	Stuifbergen, 1995
Stroke survivors	.91	King, 1996
General Population		
Graduate students	.93	Ferrans & Powers, 1985
Older women	.92	Nesbitt & Heidrich, 2000
Korean-American women	.95	Kim & Rew, 1994

Table 2. Internal Consistency Reliability of the Ferrans and Powers Quality of Life Index (QLI): Subcales

Population	Health & Functioning Subscale	Social & Economic Subscale	Psychological/ Spiritual Subscale	Family Subscale	Study
Cancer					
Breast cancer survivors	.90	.84	.93	.66	Ferrans, 1990
Melanoma patients	.92	.88	.85	.83	Cowan et al., 1992
Newly diagnosed patients	.88	.82	.82	.79	Rustoen et al., 1999b
Cardiac					
Angina pectoris (stable)	.89	.78	.88	.70	Dougherty et al., 1998
Angioplasty and bypass	.90	.89	.90	.79	Papapantonaki et al., 1994
Angioplasty and bypass	.93	.87	.90	.76	Skaggs & Yates, 1999
Arrythmias (life-threatening)	.93	.82	.90	.79	Carroll et al., 1999
Cardiac rehabilitation	.87	.73	.88	.63	Deshotels et al., 1995
End-Stage Renal Disease					
Hemodialysis patients	.87	.82	.90	.77	Ferrans & Powers, 1992
Other Illness Groups					
Chronic fatigue syndrome	.70	.84	.86	.70	Anderson & Ferrans, 1997
Stroke survivors	.86	.77	.83	.32	King, 1996
HIV+	.84	.85	.80	.92	Nunes et al., 1995

Table 3. Intervention Studies Demonstrating Sensitivity to Change

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4. Dougherty, C., Dewhurst, T., Nichol, P., & Spertus, J. (1998). Comparison of three quality of life instruments in stable angina pectoris: Seattle Angina Questionnaire, Short Form Health Survey (SF-36), and Quality of Life Index - Cardiac Version III. Journal of Clinical Epidemiology, 51(7), 569-575.

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Ferrans and Powers
QUALITY OF LIFE INDEX©
CARDIAC VERSION - IV

PART 1. For each of the following, please choose the answer that best describes how ***satisfied*** you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. The amount of chest pain (angina) that you have?	1	2	3	4	5	6
4. Your ability to breathe without shortness of breath?	1	2	3	4	5	6
5. The amount of energy you have for everyday activities?	1	2	3	4	5	6
6. Your ability to take care of yourself without help?	1	2	3	4	5	6
7. The amount of control you have over your life?	1	2	3	4	5	6
8. Your chances of living as long as your would like?	1	2	3	4	5	6
9. Your family's health?	1	2	3	4	5	6
10. Your children?	1	2	3	4	5	6
11. Your family's happiness?	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your spouse, lover, or partner?	1	2	3	4	5	6
14. Your friends?	1	2	3	4	5	6
15. The emotional support you get from your family?	1	2	3	4	5	6
16. The emotional support you get from people other than your family?	1	2	3	4	5	6

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HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
17. Your ability to take care of family responsibilities?	1	2	3	4	5	6
18. How useful you are to others?	1	2	3	4	5	6
19. The amount of worries in your life?	1	2	3	4	5	6
20. Your neighborhood?	1	2	3	4	5	6
21. Your home, apartment, or place where you live?	1	2	3	4	5	6
22. Your job (if employed)?	1	2	3	4	5	6
23. Not having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
24. Your education?	1	2	3	4	5	6
25. How well you can take care of your financial needs?	1	2	3	4	5	6
26. The things you do for fun?	1	2	3	4	5	6
27. Your chances for a happy future?	1	2	3	4	5	6
28. Your peace of mind?	1	2	3	4	5	6
29. Your faith in God?	1	2	3	4	5	6
30. Your achievement of personal goals?	1	2	3	4	5	6
31. Your happiness in general?	1	2	3	4	5	6
32. Your life in general?	1	2	3	4	5	6
33. Your personal appearance?	1	2	3	4	5	6
34. Yourself in general?	1	2	3	4	5	6
35. The changes in your life that you have had to make because of your heart problem (for example, changes diet, physical activity, and/or smoking?)	1	2	3	4	5	6

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PART 2. For each of the following, please choose the answer that best describes how *important* that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. Having no chest pain (angina)?	1	2	3	4	5	6
4. Having no shortness of breath?	1	2	3	4	5	6
5. Having enough energy for everyday activities?	1	2	3	4	5	6
6. Taking care of yourself without help?	1	2	3	4	5	6
7. Having control over your life?	1	2	3	4	5	6
8. Living as long as you would like?	1	2	3	4	5	6
9. Your family's health?	1	2	3	4	5	6
10. Your children?	1	2	3	4	5	6
11. Your family's happiness?	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your spouse, lover, or partner?	1	2	3	4	5	6
14. Your friends?	1	2	3	4	5	6
15. The emotional support you get from your family?	1	2	3	4	5	6
16. The emotional support you get from people other than your family?	1	2	3	4	5	6
17. Taking care of family responsibilities?	1	2	3	4	5	6

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HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
18. Being useful to others?	1	2	3	4	5	6
19. Having no worries?	1	2	3	4	5	6
20. Your neighborhood?	1	2	3	4	5	6
21. Your home, apartment, or place where you live?	1	2	3	4	5	6
22. Your job (if employed)?	1	2	3	4	5	6
23. Having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
24. Your education?	1	2	3	4	5	6
25. Being able to take care of your financial needs?	1	2	3	4	5	6
26. Doing things for fun?	1	2	3	4	5	6
27. Having a happy future?	1	2	3	4	5	6
28. Peace of mind?	1	2	3	4	5	6
29. Your faith in God?	1	2	3	4	5	6
30. Achieving your personal goals?	1	2	3	4	5	6
31. Your happiness in general?	1	2	3	4	5	6
32. Being satisfied with life?	1	2	3	4	5	6
33. Your personal appearance?	1	2	3	4	5	6
34. Are you to yourself?	1	2	3	4	5	6
35. The changes in your life that you have had to make because of your heart problem (for example, changes diet, physical activity, and/or smoking?)	1	2	3	4	5	6

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Ferrans and Powers
QUALITY OF LIFE INDEX©
CANCER VERSION - III

PART 1. For each of the following, please choose the answer that best describes how ***satisfied*** you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

HOW *SATISFIED* ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. The amount of pain that you have?	1	2	3	4	5	6
4. The amount of energy you have for everyday activities?	1	2	3	4	5	6
5. Your ability to take care of yourself without help?	1	2	3	4	5	6
6. The amount of control you have over your life?	1	2	3	4	5	6
7. Your chances of living as long as you would like?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your sex life?	1	2	3	4	5	6
12. Your spouse, lover, or partner?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from your family?	1	2	3	4	5	6
15. The emotional support you get from people other than your family?	1	2	3	4	5	6

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HOW *SATISFIED* ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
16. Your ability to take care of family responsibilities?	1	2	3	4	5	6
17. How useful you are to others?	1	2	3	4	5	6
18. The amount of worries in your life?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your home, apartment, or place where you live?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Not having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. How well you can take care of your financial needs?	1	2	3	4	5	6
25. The things you do for fun?	1	2	3	4	5	6
26. Your chances for a happy future?	1	2	3	4	5	6
27. Your peace of mind?	1	2	3	4	5	6
28. Your faith in God?	1	2	3	4	5	6
29. Your achievement of personal goals?	1	2	3	4	5	6
30. Your happiness in general?	1	2	3	4	5	6
31. Your life in general?	1	2	3	4	5	6
32. Your personal appearance?	1	2	3	4	5	6
33. Yourself in general?	1	2	3	4	5	6

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PART 2. For each of the following, please choose the answer that best describes how ***important*** that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

HOW *IMPORTANT* TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. Having no pain?	1	2	3	4	5	6
4. Having enough energy for everyday activities?	1	2	3	4	5	6
5. Taking care of yourself without help?	1	2	3	4	5	6
6. Having control over your life?	1	2	3	4	5	6
7. Living as long as you would like?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your sex life?	1	2	3	4	5	6
12. Your spouse, lover, or partner?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from your family?	1	2	3	4	5	6
15. The emotional support you get from people other than your family?	1	2	3	4	5	6

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HOW *IMPORTANT* TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
16. Taking care of family responsibilities?	1	2	3	4	5	6
17. Being useful to others?	1	2	3	4	5	6
18. Having no worries?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your home, apartment, or place where you live?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. Being able to take care of your financial needs?	1	2	3	4	5	6
25. Doing things for fun?	1	2	3	4	5	6
26. Having a happy future?	1	2	3	4	5	6
27. Peace of mind?	1	2	3	4	5	6
28. Your faith in God?	1	2	3	4	5	6
29. Achieving your personal goals?	1	2	3	4	5	6
30. Your happiness in general?	1	2	3	4	5	6
31. Being satisfied with life?	1	2	3	4	5	6
32. Your personal appearance?	1	2	3	4	5	6
33. Are you to yourself?	1	2	3	4	5	6

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Ferrans and Powers
QUALITY OF LIFE INDEX©
GENERIC VERSION - III

PART 1. For each of the following, please choose the answer that best describes how ***satisfied*** you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

HOW *SATISFIED* ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. The amount of pain that you have?	1	2	3	4	5	6
4. The amount of energy you have for everyday activities?	1	2	3	4	5	6
5. Your ability to take care of yourself without help?	1	2	3	4	5	6
6. The amount of control you have over your life?	1	2	3	4	5	6
7. Your chances of living as long as you would like?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your sex life?	1	2	3	4	5	6
12. Your spouse, lover, or partner?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from your family?	1	2	3	4	5	6
15. The emotional support you get from people other than your family?	1	2	3	4	5	6

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HOW *SATISFIED* ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
16. Your ability to take care of family responsibilities?	1	2	3	4	5	6
17. How useful you are to others?	1	2	3	4	5	6
18. The amount of worries in your life?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your home, apartment, or place where you live?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Not having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. How well you can take care of your financial needs?	1	2	3	4	5	6
25. The things you do for fun?	1	2	3	4	5	6
26. Your chances for a happy future?	1	2	3	4	5	6
27. Your peace of mind?	1	2	3	4	5	6
28. Your faith in God?	1	2	3	4	5	6
29. Your achievement of personal goals?	1	2	3	4	5	6
30. Your happiness in general?	1	2	3	4	5	6
31. Your life in general?	1	2	3	4	5	6
32. Your personal appearance?	1	2	3	4	5	6
33. Yourself in general?	1	2	3	4	5	6

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PART 2. For each of the following, please choose the answer that best describes how ***important*** that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

HOW *IMPORTANT* TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. Having no pain?	1	2	3	4	5	6
4. Having enough energy for everyday activities?	1	2	3	4	5	6
5. Taking care of yourself without help?	1	2	3	4	5	6
6. Having control over your life?	1	2	3	4	5	6
7. Living as long as you would like?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your sex life?	1	2	3	4	5	6
12. Your spouse, lover, or partner?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from your family?	1	2	3	4	5	6
15. The emotional support you get from people other than your family?	1	2	3	4	5	6

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HOW *IMPORTANT* TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
16. Taking care of family responsibilities?	1	2	3	4	5	6
17. Being useful to others?	1	2	3	4	5	6
18. Having no worries?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your home, apartment, or place where you live?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. Being able to take care of your financial needs?	1	2	3	4	5	6
25. Doing things for fun?	1	2	3	4	5	6
26. Having a happy future?	1	2	3	4	5	6
27. Peace of mind?	1	2	3	4	5	6
28. Your faith in God?	1	2	3	4	5	6
29. Achieving your personal goals?	1	2	3	4	5	6
30. Your happiness in general?	1	2	3	4	5	6
31. Being satisfied with life?	1	2	3	4	5	6
32. Your personal appearance?	1	2	3	4	5	6
33. Are you to yourself?	1	2	3	4	5	6

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FLANAGAN'S QUALITY OF LIFE SCALE

The Quality of Life Scale (QOLS) was developed in the United States during the 1970's to measure the quality of life. The original QOLS contained 15 items representing 5 conceptual domains of QOL: physical and material well being, relationships with other people, social and civic activities, personal development, and recreation.

The Flanagan QOLS used a seven-point likert-type scale that measured "satisfaction with needs met." The seven responses were "delighted" (7), "pleased" (6), "mostly satisfied" (5), "mixed" (4), "mostly dissatisfied" (3), "unhappy" (2), "terrible" (1).

Abbreviated Name: QOLS
Author(s): John C. Flanagan (deceased); modified by Carol S. Burckhardt
Purpose: To assess quality of life for chronic illness populations. It is also valid for healthy populations.
Population: Adult
Age Range : 18 to 100 years
Type of Instrument: Quality of life
Mode of Administration: Self - administered

Rater:	Self-administered
Time required:	5 minutes
Response Options:	7-point Likert scale
Scoring:	Global score: Minimum score: 16 / Maximum score: 112
Score Direction:	Higher scores show better QoL

Number of Items: 16
Original Language: English
Existing Translations : Danish, Farsi, German, Greek, Hebrew, Icelandic, Italian, Swedish, Mandarin Chinese, Norwegian, Portuguese, Spanish Thai, and Turkish.

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Contact for information and permission to use:

Carol Burckhardt, PhD
School of Nursing SN-5N
Oregon Health and Science University
3181 SW Sam Jackson Park Rd.
Portland, OR 97239
E-Mail: burckhac@ohsu.edu

Dimensions covered by the questionnaire :

- Material comforts (1 item)
- Health (1 item)
- Relationships (4 items)
- Participating in society (2 items)
- Self (3 items)
- Work (1 item)
- Social / Recreation (3 items)
- Independence (1 item)

Key References:

1. Flanagan JC. Research approach to improving our quality of life. Am Psychol 1978;33(2):138-147

2. Burckhardt CS, Woods SL, Schultz AA, Ziebarth DM. Quality of life of adults with chronic illness: a psychometric study. Res Nurs Health 1989;12:347-354

Reliability and validity of the Flanagan Quality of Life Scale (QOLS) were tested in four chronic illness groups. Open-ended questions and four instruments, the QOLS, Duke-UNC Health Profile (DUHP), Life Satisfaction Index (LSI-Z), and either the Arthritis Impact Measurement Scales (AIMS) or the Ostomy Adjustment Scale (OAS) were administered by telephone interview and mailed questionnaires to 227 adults three times over 6 weeks. Subjects generated verbal responses that substantiated the content validity of the QOLS. Stability reliability estimates for all instruments ranged from .53 to .90. Cronbach's alpha coefficients averaged .87 for the QOLS. Appropriate validity coefficients indicated both convergent and discriminant construct validity.

INSTRUCTIONS FOR SCORING THE QUALITY OF LIFE SCALE

This form of the Quality of **Life Scale (QOLS) has** 16 items rather than the 15 found in the original Flanagan version. Item #16, "Independence, doing for yourself" was added after a qualitative study indicated that the instrument had content validity in chronic illness groups but that it needed an item that reflected the importance to these people of remaining independent and able to care for themselves.

The instrument is scored by summing the items to make a total score. Subjects should be encouraged to fill out every item even if they are not currently engaged in it. (e.g. they can be satisfied even if they do not currently participate in organizations. Or they can be satisfied about not having children.) Missing data can be treated by entering the mean score for the item.

If you wish to compare scores in your groups with any scores that have been published, please be aware that early Burckhardt references used the 15 item scale. More recent publications use the 16 item scale. A higher score indicates better quality of life.

If you have further questions, please write to me or call.

Carol S. Burckhardt, PhD, RN
Professor of Mental Health Nursing
School of Nursing - SN-5N
Oregon Health Sciences University
3181 SW Sam Jackson Park Road
Portland, OR 97201-3098
e-mail - burckhac@ohsu.edu

References

Burckhardt CS, Woods SL, Schultz AA, Ziebarth DM (1989). Quality of life of adults with chronic illness: A psychometric study. Research in Nursing and Health, 12, 347-354.

Burckhardt, CS, Clark SR, Bennett RM (1993). Fibromyalgia and quality of life: A comparative analysis. Journal of Rheumatology, 20, 475-479.

Flanagan JC (1978). A research approach to improving our quality of life. American Psychologist, 33, 138-147.

Flanagan JC (1982). Measurement of quality of life: Current state of the art. Archives of Physical Medicine and Rehabilitation, 63, 56-59.

QUALITY OF LIFE SCALE (QOL)

Please read each item and circle the number that best describes how satisfied you are at this time. Please answer each item even if you do not currently participate in an activity or have a relationship. You can be satisfied or dissatisfied with not doing the activity or having the relationship.

	Delighted	Pleased	Mostly Satisfied	Mixed	Mostly Dissatisfied	Unhappy	Terrible
1. Material comforts home, food, conveniences, financial security	7	6	5	4	3	2	1
2. Health - being physically fit and vigorous	7	6	5	4	3	2	1
3. Relationships with parents, siblings & other relatives- communicating, visiting, helping	7	6	5	4	3	2	1
4. Having and rearing children	7	6	5	4	3	2	1
5. Close relationships with spouse or significant other	7	6	5	4	3	2	1
6. Close friends	7	6	5	4	3	2	1
7. Helping and encouraging others, volunteering, giving advice	7	6	5	4	3	2	1
8. Participating in organizations and public affairs	7	6	5	4	3	2	1
9. Learning- attending school, improving understanding, getting additional knowledge	7	6	5	4	3	2	1
10. Understanding yourself - knowing your assets and limitations - knowing what life is about	7	6	5	4	3	2	1
11. Work - job or in home	7	6	5	4	3	2	1
12. Expressing yourself creatively	7	6	5	4	3	2	1
13. Socializing - meeting other people, doing things, parties, etc	7	6	5	4	3	2	1
14. Reading, listening to music, or observing entertainment	7	6	5	4	3	2	1
15. Participating in active recreation	7	6	5	4	3	2	1
16. Independence, doing for yourself	7	6	5	4	3	2	1

FUNCTIONAL LIMITATIONS PROFILE

The Functional Limitations Profile (FLP), a British version of US Symptom Impact Profile (SIP) is a well established measure of the effects of disease on behaviour that is sensitive to the effects of rehabilitation.

Abbreviated Name: FLP
Author(s): Donald L. Patrick
Purpose: Translation of the Sickness Impact Profile (SIP) into UK English
Population: Adult
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-/ Interviewer-administered
Time required:	20-30 minutes
Response Options:	Respondent is asked to tick the statements he/she agrees with or considers due to his/her health.
Scoring:	Global score Scores by dimension
Score Direction:	Lower scores show better QoL
Weighting:	Yes

Number of Items: 136
Original Language: English

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Contact for information and permission to use:

Donald L Patrick, Ph.D., M.S.P.H.
Professor and Director
Social and Behavioral Sciences Program
Box 357660
Department of Health Services
School of Public Health and Community Medicine
University of Washington
H-689 Health Sciences
Seattle, WA 98195-7660, USA
Phone: (206) 616-2981
Fax: 206-543-3964
E-Mail: donald@u.washington.edu

Dimensions covered by the questionnaire :

- Physical:
  - Ambulation (12 items)
  - Body care and movement (23 items)
  - Mobility (10 items)
  - Household management (10 items)
- Psychosocial:
  - Recreation and pastime (8 items)
  - Social interaction (20 items)
  - Alertness (10 items)
  - Sleep and rest (7 items)
- Emotion (9 items)
- Eating (9 items)
- Communication (9 items)
- Work (9 items)

Key References:

1. Patrick DL et al. Disablement and care: a comparison of patient views and general practitioner knowledge. Journal of the Royal College of General Practitioners 1982;32:429-434

2. Charlton J et al. Use of the multivariate measures of disability in health surveys. Journal of Epidemiology and Community Health 1983;37:296-304

FUNCTIONAL LIMITATIONS PROFILE (FLP)

INSTRUCTIONS FOR ADMINISTRATION

The following instructions are for the INTERVIEWER-ADMINISTERED QUESTIONNAIRE (NOTE: These differ from the Sickness Impact Profile to permit response to each item rather than responses only to items considered to apply to the respondent and are related to health. This change was made to improve the validity of responses from older adults and persons with disabilities.)

SAY TO ALL VERBATIM

I want to talk to you about the things you usually do every day. I am going to read out some statements which describe things people often do when they are not well. Even if you think you are well, some of these statements may stand out, because they describe you and are related to your health. Listen to each statement, think of yourself today and tell me if it describes you or not.

For example, I might read the statement, "I am not driving my car." If you agree with this statement, you should tell me (agree/disagree is the best response pattern). I will then ask, "Is this due to your health?" Please answer "yes" or "no." If you have not been driving for some time due to your health and are still not driving today, you should respond "agree." (If respondents have never driven a car but have used public transportation such as a bus or train, substitute "using public transport").

(IF RESPONDENT IS IN HOSPITAL) If you are in hospital today, you are here because of your state of health, and you are not doing a number of the things you usually do. For instance, if driving is usual for you, then you are not driving today because you are in hospital, and you should agree with this statement.
If you never drive or are not driving today because your car is being repaired, you should not respond that the statement is due to your health.
Ask me to repeat a statement or slow down if you do not understand. Remember we are interested in both recent or longstanding changes in your health.

The following instructions are for the SELF-ADMINISTERED QUESTIONNAIREs:

Introduction to the Respondent

We are interested in the activities that you do in carrying on your life and any changes that describe you today that are related to your health.

This booklet lists statements that describe things people often do when they are not well. Even if you think you are well, some of these statements may stand out, because they describe you and are related to your health. As you read each statement in the questionnaire, think of yourself today. When you read a statement that describes you and is related to your health, place a tick on the line to the right of the statement. For example:

I am not driving my car _____

If you have not been driving for some time because of your health and are still not driving today, you should tick this statement. On the other hand, if you never drive or are not driving today because you car is being repaired, you should not tick it. Tick a statement only if you are sure it describes you and is due to health.

NOTE: At the bottom of each page of the self-administered questionnaire, you may wish to ask the respondent to indicate that he or she has read all statements on the page by ticking the following statement:

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE _____

This helps to ensure that respondents have read all the items on the page and that a page with no ticks does not indicate missing data.

OTHER CONSIDERATIONS

The Functional Limitations Profile, based on the same theoretical development but with different psychometric properties from the Sickness Impact Profile, was developed to give a point-in-time estimate of sickness-related dysfunction. The focus on "today" is used to help ensure that all respondents are using the same reference point and recall period. For items that ask for change, i.e., "eating less than usual", the respondent is requested to think of their behavior or health on the day of the enquiry and compare it with what they have done usually prior to the day of enquiry. This prior period may vary for each respondent and contribute to their response concerning "today".

It is extremely important in interviewer-administration of the FLP that interviewers do not break their rhythm in reading items and obtaining responses. It is advisable to establish a pattern of questioning, avoiding eye contact if possible, at this point of the interview.

Many queries may arise when administering the FLP in-person or supervising self-administration of the instrument.

Following are some standardized responses when queries arise.

ANSWERING QUERIES THAT MAY ARISE

"I've never been able to do that." SAY: Yes, we do want to know about things you have never been able to do.

"I've not been able to do that for some time." SAY: We want to know about all recent or long-standing changes in the things you do.

"Some days I can do that, some days I can't." SAY: Think of yourself today.

"It's due to my age." SAY: Would you say that was due to your health or not?

"None of this applies to me; I'm perfectly health." SAY: A few of the statements may apply to you. It is therefore important that we do check them all, since we are comparing healthy people with less healthy people.

"I retired because of my age, not my health" "I have never been employed for wages." SAY: None of the statements in the work category apply to you. Therefore you do not tick (respond to) any of these items because they do not apply to you.

SCORING INSTRUCTIONS

There are twelve category scores, two dimension scores, and an overall FLP score are derived using British weights. These weights are not identical to those used for the Sickness Impact Profile, since they were derived from a British population.

CATEGORY SCORES

The percent score is calculated for each category by adding the scale values for each item with which the respondent agrees and considers due to his/her health (or ticked items) and dividing by the maximum possible dysfunction score for the FLP. This figure is then multiplied by 100 to obtain the FLP category score.

DIMENSION SCORES

Two dimension scores may be calculated. The physical dimension score is obtained by adding the scale values for each item with which the respondent agrees and considers due to his/her health (or ticked items) with the categories of AMBULATION, BODY CARE AND MOVEMENT, MOBILITY, AND HOUSEHOLD MANAGEMENT, dividing by the maximum possible dysfunction score for these categories (4355), and then multiplying by 100. The psychosocial dimension score is obtained by adding the scale values for each item ticked within RECREATION AND PASTIME, SOCIAL INTERACTION, EMOTION, ALERTNESS, AND SLEEP AND REST, dividing by the maximum possible dysfunction score for these categories (3667), and then multiplying by 100. The scores for the remaining categories are always calculated individually.

OVERALL FLP SCORE

The overall score for the FLP is calculated by adding the scale values for each item with which the respondent agrees and considers due to his/her health (or ticked items) across all 12 categories and dividing by the maximum possible dysfunction score for the FLP (9933). This figure is then multiplied by 100 to obtain the FLP overall score.
Each item within the 12 categories is listed on the following pages along with the scale values coded to one decimal as follows:

1. Only items with which the respondent agrees and considers due to his/her health (or ticked items) should be included in the calculations for FLP category, dimension, and overall score.

2. Following each item is the scale value or weight for that item e.g., item 1 has a scale value of 5.4

3. The maximum possible scale value is shown following the title of each category e.g., the ambulation category has a maximum possible score of 100.6.

4. The maximum possible score for the physical dimension is 444.5 while the maximum possible score for the psychosocial dimension is 366.7.

5. The maximum possible score for the FLP is 9933 which is the denominator for calculating the percent score for the entire FLP.

6. A special case of category and FLP overall score concerns the work category. Item 128 has a weight of 361 indicating an unusually high scale value. The scale value for this item has been statistically adjusted to take into account the fact that when item 128 is ticked no other item in the work category can been ticked. Please note that the maximum possible score for the work category is not the sum of the individual items, but is instead 70% of the total. This value was determined using the distribution of scores on the work category.

Also, with respect to the work category there are two special considerations in scoring:

1. When a respondent agrees with either,

"If you are retired, was your retirement due to your health? or

"If you are not retired, but are not working, is this due to your health?

he or she is instructed to skip Category W- Work. In scoring the questionnaire for respondents who answer Yes to either of these questions, item 128 should be ticked.

AMBULATION ITEMS (MAXIMUM POSSIBLE SCORE = 1006)

The following statements describe walking and use of stairs. Remember, think of yourself today. If 'AGREE,' PROBE; Is this due to your health?

ITEM & WEIGHT

1. I walk shorter distances or often stop for a rest. -(054)

2. I do not walk up or down hills. -(064)

3. I only use stairs with a physical aid; for example, a handrail, stick -(082)or crutches.

4. I only go up and down stairs with assistance from someone else. -(087)

5. I get about in a wheelchair. -(121)

6. I do not walk at all. -(126)

7. I walk by myself but with some difficulty; for example, I limp, wobble, stumble or I have a stiff leg. -(071)

8. I only walk with help from someone else. -(098)

9. I go up and down stairs more slowly; for example, one step at a time or I often have to stop. -(062)

10. I do not use stairs at all. -(106)

11. I get about only by using a walking frame, crutches, stick, walls, or hold on to furniture.
-(096)

12. I walk more slowly. -(039)

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE _____

BODY CARE AND MOVEMENT ITEMS (MAXIMUM POSSIBLE SCORE = 1927)

The following statements describe how you move about, bath, go to the toilet, dress yourself today. If 'AGREE', PROBE: Is this due to your health?

13. I make difficult movements with help; for example getting in or out of the bath or car. -(082)

14. I do not get in and out of bed or chairs without the help of a person or mechanic aid. -(100)

15. I only stand for short periods of time. -(067)

16. I do not keep my balance.-(093)

17. I move my hands or fingers with some difficulty or limitation. -(066)

18. I only stand up with someone's help. -(093)

19. I kneel, stoop or bend down only by holding onto something. -(061)

20. I am in a restricted position all the time. -(124)

21. I am very clumsy. -(047)

22. I get in and out of bed or chairs by grasping something for support or by using a stick or walking frame. -(079)

23. I stay lying down most of the time. -(120)

24. I change position frequently. -(0513)

25. I hold onto something to move myself around in bed. -(082)

26. I do not bathe myself completely; for example, I need help with bathing.-(085)

27. I do not bathe myself at all, but am bathed by someone else. -(100)

28. I use a bedpan with help. -(107)

29. I have trouble putting on my shoes, socks, or stockings. -(054)

30. I do not have control of my bladder. -(122)

31. I do not fasten my clothing; for example, I require assistance with buttons, zips or shoelaces. -(068)

32. I spend most of the time partly dressed or in pajamas. -(075)

33. I do not have control of my bowels. -(124)

34. I dress myself, but do so very slowly. -(043)

35. I only get dressed with someone's help. -(082)

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE_____

MOBILITY ITEMS (MAXIMUM POSSIBLE SCORE = 0727)

These next statements describe how you get about the house and outside If 'AGREE' PROBE: Is this due to your health?

36. I only get about in one building. -(076)

37. I stay in one room. -(101)

38. I stay in bed more. -(091)

39. I stay in bed most of the time. -(114)

40. I do not use public transport now. -(052)

41. I stay at home most of the time. -(079)

42. I only go out if there is a lavatory nearby. -(064)

43. I do not go into town. -(047)

44. I only stay away from home for short periods. -(046)

45. I do not get about in the dark or in places that are not lit unless I have someone to help -(057)

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE_____

HOUSEHOLD MANAGEMENT ITEMS (MAXIMUM POSSIBLE SCORE = 0695)

The following statements describe your daily work, around the home. When you answer, think of yourself today. If 'AGREE' PROBE: Is this due to your health?

46. I only do housework or work around the house for short periods of time or I rest often. -(050)

47. I do less of the daily household chores than I would usually do. -(037)

48. I do not do any of the daily household chores that I would usually do. -(090)

49. I do not do any of the maintenance or repair work that I would usually do in my home or garden. -(075)

50. I do not do any of the shopping that I would usually do. -(084)

51. I do not do any of the cleaning that I would usually do. -(078)

52. I have difficulty using my hands; for example, turning taps, using kitchen gadgets, sewing or doing repairs.-(078)

53. I do not do any of the clothes washing that I would usually do. -(075)

54. I do not do heavy work around the house. -(059)

55. I have given up taking care of personal or household business affairs; for example, paying bills, banking or doing household accounts. -(069)

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE_____
(MAXIMUM POSSIBLE PHYSICAL DIMENSION SCORE = 4355)

RECREATION AND PASTIME ITEMS (MAXIMUM POSSIBLE SCORE = 0383)

The following statements describe the activities you usually do in your spare time, for relaxation, entertainment or just to pass the time. Again, think of yourself today. If 'AGREE' PROBE: Is this due to your health?

56. I spend shorter periods of time on my hobbies and recreation. -(032)

57. I go out less often to enjoy myself. -(027)

58. I am cutting down on some of my usual inactive pastimes; for example, I watch TV less, play cards less, or read less. -(050)

59. I am not doing any of my usual inactive pastimes; for example, I do not watch TV, play cards, or read. -(091)

60. I am doing more inactive pastimes instead of my other usual activities.-(043)

61. I take part in fewer community activities. -(025)

62. I am cutting down on some of my usual physical recreation or more active pastimes. -(034)

63. I am not doing any of my usual physical recreation or more active pastimes. -(081)

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE_____

SOCIAL INTERACTION ITEMS (MAXIMUM POSSIBLE SCORE = 1289)
These statements describe your contact with family and friends today. If 'AGREE' PROBE: Is this due to your health?

64. I go out less often to visit people. -(031)

65. I do not go out at all to visit people. -(091)

66. I show less interest in other people's problems; for example, I don't listen when they tell me about their problems; I don't offer to help. -(050)

67. I am often irritable with those around me; for example, I snap at people or criticize easily. -(064)

68. I show less affection. -(044)

69. I take part in fewer social activities than I used to; for example, I go to fewer parties or social events. -(025)

70. I am cutting down the length of visits with friends. -(031)

71. I avoid having visitors. -(073)

72. My sexual activity is decreased. -(064)

73. I often express concern over what might be happening to my health.-(044)

74. I talk less with other people. -(044)

75. I make many demands on other people; for example, I insist that they do things for me or tell them how to do things. -(076)

76. I stay alone much of the time. -(091)

77. I am disagreeable with my family; for example, I act spitefully or stubbornly. -(086)

78. I frequently get angry with my family; for example, I hit them, scream or throw things at them. -(103)

79. I isolate myself as much as I can from the rest of my family. -(100)

80. I pay less attention to the children. -(059)

81. I refuse contact with my family; for example, I turn away from them. -(109)

82. I do not look after my children or family as well as I usually do. -(066)

83. I do not joke with members of my family as much as I usually do. -(038)

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE_____

EMOTION ITEMS (MAXIMUM POSSIBLE SCORE = 0693)

The next statements describe your feelings and behavior. Again, think of yourself today. If 'AGREE' PROBE: Is this due to your health?

84. I say how bad or useless I am; for example, that I am a burden -(089) on others.

85. I laugh or cry suddenly. -(058)

86. I often moan and groan because of pain or discomfort. -(067)

87. I have attempted suicide. -(141)

88. I behave nervously or restlessly. -(048)

89. I keep rubbing or holding areas of my body that hurt or are uncomfortable. -(059)

90. I am irritable and impatient with myself; for example, I run myself down, I swear at myself, I blame myself for things that happen. -(079)

91. I talk hopelessly about the future. -(096)

92. I get sudden frights. -(056)

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE_____

ALERTNESS ITEMS (MAXIMUM POSSIBLE SCORE = 0711)

93. I am confused and start to do more than one thing at a time.-(074)

94. I have more minor accidents; for example, I drop things, I trip and fall, or I bump into things. -(090)

95. I react slowly to things that are said or done.-(052)

96. I do not finish things I start.-(045)

97. I have difficulty reasoning and solving problems; for example, making plans, making decisions, or learning new things. -(078)

98. I sometimes get confused; for example, I do not know where I am, who is around, or what day it is. -(115)

99. I forget a lot; for example, things that happened recently, where I put things, or to keep appointments. -(085)

100. I do not keep my attention on any activity for long. -(052)

101. I make more mistakes than usual. -(049)

102. I have difficulty doing things which involve thought and concentration. -(071)

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE_____

SLEEP AND REST ITEMS (MAXIMUM POSSIBLE SCORE = 0591)

These statements describe your sleep and rest activities today. If 'AGREE' PROBE: Is this due to your health?

103. I spend much of the day lying down to rest. -(096)

104. I sit for much of the day. -(062)

105. I sleep or doze most of the time, day and night. -(111)

106. I lie down to rest more often during the day. -(072)

107. I sit around half asleep. -(084)

108. I sleep less at night; for example, I wake up easily, I don't fall asleep for a long time, or I keep waking up. -(086)

109. I sleep or doze more during the day. -(080)

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE_____

(MAXIMUM POSSIBLE PSYCHOSOCIAL DIMENSION SCORE = 3667)

EATING ITEMS (MAXIMUM POSSIBLE SCORE = 0706)

The following statements describe your eating and drinking habits. If 'AGREE' PROBE: Is this due to your health?

110. I eat much less than usual. -(034)

111. I feed myself but only with specially prepared food or special utensils. -(076)

112. I eat special or different food; for example, I follow a soft food, bland, low salt, low fat, or low sugar diet. -(052)

113. I eat no food at all, but I take liquids. -(113)

114. I just pick or nibble at my food. -(039)

115. I drink less fluids. -(033)

116. I feed myself with help from someone else. -(095)

117. I do not feed myself at all but have to be fed. -(121)

INTERVIEWER MAY CODE:

118. I eat no food at all except by tubes or intravenous infusion. -(143)

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE_____

COMMUNICATION ITEMS (MAXIMUM POSSIBLE SCORE = 0685)

I am going to read out some statements about how much you talk to other people and write. Please think about yourself today. If 'AGREE' PROBE: Is this due to your health?

119. I have trouble writing or typing. -(050)

120. I communicate mostly by nodding my head, pointing, or using sign language, or other gestures. -(127)

121. My speech is understood only by a few people who know me well. -(094)

122. I often lose control of my voice when I talk; for example, my voice gets louder or softer or changes unexpectedly. -(059)

123. I don't write except to sign my name. -(084)

124. I carry on a conversation only when very close to other people or looking directly at them. -(059)

125. I speak with difficulty; for example, I get stuck for words, I stutter, I stammer, I slur my words. -(076)

126. I am understood with difficulty. -(089)

127. I do not speak clearly when I am under stress. -(047)

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE_____

WORK ITEMS (MAXIMUM POSSIBLE SCORE = 0520)

I am going to read out some statements about work. As I read them out think of yourself today. If today is not a working day for you, think about your last working day. If 'AGREE' PROBE: Is this due to your health?

SELF ADMINISTERED: The next group of statements has to do with any work you usually do other than managing your home. By this we mean anything that you regard as work that you do on a regular basis.

Do you usually do work other than managing your home? YES NO IF YES, COMPLETE THE WORK SECTION.

IF NO:

Are you retired? YES NO

If you are retired, was your retirement due to your health? YES NO

If you are not retired, but are not working, is this due to your health? YES NO

IF YES, PLEASE TICK ITEM 123 AND SKIP THE REST OF THE ITEMS IN THIS SECTION.

IF NO, PLEASE SKIP THIS SECTION.

128. I do not work at all (INCLUDES RETIRED BECAUSE OF HEALTH) -(361)

129. I do part of my job at home. -(040)

130. I am not getting as much work done as usual. -(041)

131. I often get irritable with my workmates; for example, I snap at them or criticize them easily. -(042)

132. I work shorter hours. -(052)

133. I only do light work. -(056)

134. I only work for short periods of time or often stop to rest. -(065)

135. I work at my usual job but with some changes; for example, I use different tools or special aids or I swap jobs with someone else. -(036)

136. I do not do my job as carefully and accurately as usual. -(050)

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE_____
(MAXIMUM POSSIBLE FLP SCORE = 10023)

FUNCTIONAL STATUS QUESTIONNAIRE

The Functional Status Questionnaire (FSQ) can be used as a self-administered functional assessment for a patient. The FSQ provides information on the patient's physical, psychological, social and role functions. It can be used both to screen initially for problems and to monitor the patient over time.

Abbreviated Name: FSQ
Author(s): Alan Jette
Purpose: To provide a comprehensive and feasible assessment of physical, psychological, social and role function in ambulatory patients.
Population: Adult
Age Range : 18+ years
Type of Instrument: Quality of life, Disability/ Physical Functioning
Mode of Administration:

Rater:	Self-administered
Time required:	15 minutes
Response Options:	4-7 point Likert scale
Scoring:	Global score: Minimum score: 0 / Maximum score: 100 Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 34
Original Language: English
Existing Translations : Dutch, French, German, Italian, Swedish

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Contact for information and permission to use:

Professor Alan Jette
Dean, Sargent College of Health
and Rehabilitation Sciences
Boston University
635 Commonwealth Ave
Boston, MA 02215 USA
E-Mail: ajette@bu.edu

Dimensions covered by the questionnaire :

- Affective well-being (10 items)
- Daily activities (12 items)
- Health perception (1 item)
- Social activities (3 items)
- Sexual function (1 item)
- Usual social role (7 items)

Key References:

1. Cleary Pd, Jette AM. Reliability and validity of the functional status questionnaire. Quality of Life Research 2000;9(6a):747-753

2. Jette Am, Davies Ar, Cleary Pd Et Al. The functional status questionnaire: reliability and validity when used in primary care. J Gen Intern Med. 1986 ;1:143-9.

A comprehensive functional assessment requires thorough and careful inquiry, which is difficult to accomplish in most busy clinical practices. This paper examines the reliability and validity of the Functional Status Questionnaire (FSQ), a brief, standardized, self-administered questionnaire designed to provide a comprehensive and feasible assessment of physical, psychological, social and role function in ambulatory patients. The FSQ can be completed and computer-scored in minutes to produce a one-page report which includes six summated-rating scale scores and six single-item scores. The clinician can use this report both to screen for and to monitor patients' functional status. In this study, the FSQ was administered to 497 regular users of Boston's Beth Israel Hospital's Healthcare Associates and 656 regular users of 76 internal medicine practices in Los Angeles. The data demonstrate that the FSQ produces reliable sub-scales with construct validity. The authors believe the FSQ addresses many of the problems behind the slow diffusion into primary care of systematic functional assessment.

THE BETH ISRAEL/UCLA
FUNCTIONAL STATUS QUESTIONNAIRE
A USER'S GUIDE

Robert Brook, M.D., Sc.D.

David Calkins, M.D., M.P.P.

Paul Cleary, Ph.D.

Allyson Davies, M.P.H.

Thomas Delbanco, M.D.

Arlene Fink, Ph.D., M.A.

Alan Jette, Ph.D.

Jacqueline Kosecoff, Ph.D., M.S.

Lisa Rubenstein, M.D., M.P.H.

Roy Young, M.D.

THE BETH ISRAEL/UCLA FUNCTIONAL STATUS QUESTIONNAIRE (FSQ)

The Beth Israel/UCLA Functional Status Questionnaire (FSQ) is a short, self-administered questionnaire that is designed to measure the physical, social, and psychological level at which patients are functioning in daily life. It can be administered in the doctor's office, clinic, or patient's home, and takes an average of 15 minutes to complete. Scoring is done by computer. The FSQ is based on other well accepted, extensively studied questionnaires, but is tailored to meet the needs of an internal medicine practice composed of a wide range of patients with chronic illnesses.

The FSQ may be found in Appendix I of this guide. It is divided into five sections, each preceded by a brief set of instructions. The first section, Daily Activities, consists of 12 items that measure basic activities of daily living (e.g., eating, bathing and dressing), intermediate activities of daily living (e.g., walking several blocks), and social activities (e.g., visiting with relatives or friends). In this section, patients respond in terms of how difficult it is to perform these activities and whether the difficulty is health-related.

The second section, General Functioning, consists of five items about general health (e.g., number of bed days) and role functioning (e.g., ability to do certain kinds or amounts of work). Patients are asked to recall their behavior in the past one to three months and report their level of satisfaction with their health.

The third section, Well-Being, contains 10 items that measure mental health and the quality of social interactions. For each item, patients are asked to describe how often they have had certain feelings in the past month.

The fourth section, Social Activities, consists of three questions that ask about number and amount of contact with friends and relatives, and satisfaction with sexual relationships.

The last section, Employment, contains seven items that measure employment status and performance on the job.

The patient's scores on the FSQ are reported on a special form. A sample report is given.

Function Status Report for: DAISY MAE ID: 6789 Age: 62

Physician: MARK REED Date of Questionnaire: 01/29/84

```
BASIC ACTIVITY:  ++++++++++++++++33++++++++++++++++++++++++++------
INTERMEDIATE:    ++++++++++++++28++++++++++++++++++++++--------------
MENTAL HEALTH:   ++++++++++++++++++++++48+++++++-----------------
SOCIAL ACTIVITY: ++++++++++++++++++++++44+++++++++++++++-----------
INTERACTION:     ++++++++++++++++++++++++++++++++++++++++++++++++100
EMPLOYMENT: RETIRED BECAUSE OF HEALTH
```

Major Problems: doing self-care, moving to a chair, climbing stairs.
Minor problems: visiting friends, participating in outside activities.
Last month: days in bed = 3 ; restricted days = 7 .
The above problems are chronic.

Mostly: nervous, happy, affectionate, amiable.
Seldom: peaceful, downhearted, depressed, isolated, irritable, demanding.
Social contact : once a month (friends = 0).
Did not have any sexual relationships.

The report begins with the patient's name, sex, age, medical record number, the date the FSQ was administered, and the physician's name. Next, the items on the FSQ are organized according to five types of functioning: physical, psychological, role, social, and general (e.g., bed days, sexual relationships). Within each type, scores are reported for individual items or for combined groups of items (called indexes). Within the psychological functioning section, for example, there are five conceptually related items that are combined to form a mental health index. Scores range from 0 to 100. A score of 100 indicates an absence of disability.

To help interpret the individual scores, a "warning zone" is indicated by plus signs . A group of general internists reviewed the questionnaire and the construction of the indexes and agreed on a score below which a physician should be concerned. Values below this level (which we will refer to as the "warning level") are considered to represent clinically significant impairment. For example, for mental health, scores below 66 are likely to represent significant impairment.

The report concludes with a summary of the patient's scores.

A detailed discussion of each section of the report follows.

Function Status Report for: DAISY MAE ID: 6789 Age: 62

Physician: MARK REED Date of Questionnaire: 01/29/84

```
BASIC ACTIVITY: ++++++++++++++++33++++++++++++++++++++++------
INTERMEDIATE:   ++++++++++++++28++++++++++++++++++++----------
```

Physical functioning is measured by indexes that describe two types of activities. First, the Basic Activities of Daily Living Index assesses activities that are performed by many healthy people every day or at frequent intervals. This index is based on three items that determine if the patient can:

- #1: eat, bathe, and dress
- #2: move in and out of bed and/or chairs
- #5: walk indoors, such as around the house

The warning level is 89. In the example presented, Daisy Mae received a score of 33, within the warning zone.

The second index, Intermediate Activities of Daily Living, measures activities that require greater degrees of mobility or cardiovascular capacity. This index is based on six items from the FSQ:

- #3: walking several blocks
- #4: walking one block or climbing one flight of stairs
- #6: doing house or yard work
- #7: doing errands, such as grocery shopping

Ø8: driving or using public transportation

Ø12: participating in vigorous recreational activities

The warning level is 72. The report shows that Daisy Mae achieved a score of 28 on the intermediate index. This is well within the warning zone and is therefore cause for concern.

MENTAL HEALTH: ++++++++++++++++++++++++48++++++----------

Psychological functioning includes a Mental Health Index. The items contained in it indicate the frequency of feeling anxious, depressed, or generally happy over a month's time. The five items that constitute the Mental Health Index are:

Ø18: feeling nervous

Ø19: feeling calm and peaceful

Ø20: feeling down-hearted and blue

Ø21: feeling happy

Ø22: feeling down in the dumps

A score below 66 is reason for concern. In the illustrated report, Daisy Mae has a score of 48.

EMPLOYMENT: RETIRED BECAUSE OF HEALTH

Role function is reported in terms of one question and one index. The question is #31 on the FSQ, which asks about the patient's work situation during the past month. Possible responses are: working full-time, working part-time, unemployed, looking for work, unemployed because of health, retired because of health, retired for other reasons, and other. Daisy Mae responded that she had retired for health reasons.

The index is called Work Performance and is based on six items, each scaled from "all of the time" to "none of the time":

#32: did as much work as others

#33: worked for short periods of time because of health

#34: worked regular hours

#35: did job carefully

#36: worked at usual job with some changes

#37: feared losing job due to health

The warning level for work performance is 75. Daisy Mae did not score on this index, as she is retired.

```
SOCIAL ACTIVITY: ++++++++++++++++++++++44++++++++++++++----------
INTERACTION:     ++++++++++++++++++++++++++++++++++++++++++++++100
```

Social functioning is described by two indexes and one item that is scored individually. The first index, Social Activity, is comprised of three items:

- #9: visit with relatives or friends
- #10: participate in community activities
- #11: take care of other people

The warning level for social activities of daily living is 78. Daisy Mae scored 44, which should prompt concern.

The second index is Quality of Interaction. It consists of five items that ask a person to describe feelings in the past month with respect to:

- #23: isolation
- #24: affection toward others
- #25: irritability
- #26: demands on family and friends
- #27: getting along well with others

The warning level for the index is 61. Daisy Mae scored 100. It is likely that she is functioning well in social interactions.

Item #29, which is reported separately, asks how often the respondent was together with friends or relatives in the past month. The possible responses are: every day, several times a week, about once a week, two or three times during the month, about once a month, and not at all. Daisy Mae responded "every day", indicating regular social contact.

The next section of the report contains four separate items. The first item, #13 on the FSQ, asks how many days the repondent has spent in bed due to poor health during the past month. Number of days in bed, in this case 3, are indicated on the report.

The second item, #14, asks if the respondent had to cut down for one half day or more on the things he or she usually does because of illness or injury in the past month. The response on the report indicates the number of days. Daisy Mae reported 7 restricted activity days.

The third item, #30, asks how satisfied the respondent is with sexual relationships during the past month. The possible responses are: very satisfied, satisfied, not sure, dissatisfied, very dissatisfied, and did not have any sexual relationships. Daisy Mae did not have any sexual relationships.

The final item, #17, asks the respondent how satisfied he or she is with his or her health. The possible responses are: very satisfied, satisfied, not sure, dissatisfied, and very dissatisfied. Daisy Mae is dissatisfied.

```
Is dissatisfied with health.
Major Problems: doing self-care, moving to a chair, climbing stairs.
Minor problems: visiting friends, participating in outside activities.
Last month: days in bed = 03; restricted days = 07.
The above problems are chronic.

Mostly: nervous, happy, affectionate, amiable.
Seldom: peaceful, downhearted, depressed, isolated, irritable, demanding.
Social contact : once a month (friends = 00).
Did not have any sexual relationships.
```

The final section of the report, Summary, reviews the patient's scores on the various indexes. If there is an unacceptable score on basic activities of daily living, intermediate activities of daily living, work performance, or social activities, the report notes individual items contributing to this score.

Functional Status Questionnaire

INSTRUCTIONS

This questionnaire will provide the Beth Israel/UCLA Functional Assessment Study with important information about your health.

All information that would permit you to be identified as a member of the study will be regarded as strictly confidential and will be used only for this study. Your name will not appear on the questionnaire. The number on top of this page will allow us to keep track of who returns each questionnaire.

Please read carefully each question in this booklet. Circle the number of the answer that most closely fits you.

For example:

1. HAVE YOU EVER HAD A COLD? **(Circle one)**
YES ..... (1)
NO 2

Please try to answer every question that applies to you. If none of the answers provided seems exactly right, choose the one that comes nearest to being right for you.

Please read carefully the instructions provided at the beginning of each section.

Please begin on the next page

DAILY ACTIVITIES

This group of questions refers to many types of physical and social activities. We would like to know how **difficult** it was for you to do each of these activities, on the average, **during the past month.** By difficult, we mean how hard it was or how much physical effort it took to do the activity **because of your health.** Circle the number:

4 if you usually had **no difficulty** doing it;
3 if you usually had **some difficulty** doing it;
2 if you usually had **much difficulty** doing it;
1 if you usually **did not do the activity because of your health;** or
0 if you usually **did not do the activity for other reasons.**

DURING THE PAST MONTH, HOW MUCH PHYSICAL DIFFICULTY DID YOU HAVE...	USUALLY DID WITH NO DIFFICULTY	USUALLY DID WITH SOME DIFFICULTY	USUALLY DID WITH MUCH DIFFICULTY	USUALLY DID NOT DO BECAUSE OF HEALTH	USUALLY DID NOT DO FOR OTHER REASONS
1. Taking care of yourself, that is, eating, dressing, or bathing?	4	3	2	1	0
2. Moving in and out of a bed or chair?	4	3	2	1	0
3. Walking several blocks?	4	3	2	1	0
4. Walking one block or climbing one flight of stairs?	4	3	2	1	0
5. Walking indoors, such as around your home?	4	3	2	1	0
6. Doing work around the house such as cleaning, light yard work, home maintenance?	4	3	2	1	0
7. Doing errands, such as grocery shopping?	4	3	2	1	0
8. Driving a car or using public transportation?	4	3	2	1	0
9. Visiting with relatives or friends?	4	3	2	1	0
10. Participating in community activities, such as religious services, social activities, or volunteer work?	4	3	2	1	0
11. Taking care of other people such as family members?	4	3	2	1	0
12. Doing vigorous activities such as running, lifting heavy objects or participating in strenuous sports?	4	3	2	1	0

Functional Status Questionnaire

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For example:

1. HAVE YOU EVER HAD A COLD? **(Circle one)**
YES ..... (1)
NO 2

Please try to answer every question that applies to you. If none of the answers provided seems exactly right, choose the one that comes nearest to being right for you.

Please read carefully the instructions provided at the beginning of each section.

Please begin on the next page

DAILY ACTIVITIES

This group of questions refers to many types of physical and social activities. We would like to know how **difficult** it was for you to do each of these activities, on the average, **during the past month.** By difficult, we mean how hard it was or how much physical effort it took to do the activity **because of your health.** Circle the number:

4 if you usually had **no difficulty** doing it;
3 if you usually had **some difficulty** doing it;
2 if you usually had **much difficulty** doing it;
1 if you usually **did not do the activity because of your health;** or
0 if you usually **did not do the activity for other reasons.**

DURING THE PAST MONTH, HOW MUCH PHYSICAL DIFFICULTY DID YOU HAVE...	USUALLY DID WITH NO DIFFICULTY	USUALLY DID WITH SOME DIFFICULTY	USUALLY DID WITH MUCH DIFFICULTY	USUALLY DID NOT DO BECAUSE OF HEALTH	USUALLY DID NOT DO FOR OTHER REASONS
1. Taking care of yourself, that is, eating, dressing, or bathing?	4	3	2	1	0
2. Moving in and out of a bed or chair?	4	3	2	1	0
3. Walking several blocks?	4	3	2	1	0
4. Walking one block or climbing one flight of stairs?	4	3	2	1	0
5. Walking indoors, such as around your home?	4	3	2	1	0
6. Doing work around the house such as cleaning, light yard work, home maintenance?	4	3	2	1	0
7. Doing errands, such as grocery shopping?	4	3	2	1	0
8. Driving a car or using public transportation?	4	3	2	1	0
9. Visiting with relatives or friends?	4	3	2	1	0
10. Participating in community activities, such as religious services, social activities, or volunteer work?	4	3	2	1	0
11. Taking care of other people such as family members?	4	3	2	1	0
12. Doing vigorous activities such as running, lifting heavy objects or participating in strenuous sports?	4	3	2	1	0

13. During the past month, how many days did illness or injury keep you in bed all or most of the day? **(If none, write "0")**

_____ **DAYS IN BED** during the past month

14. During the past month, how many days did you cut down on the things you usually do for one-half day or more because of your own illness or injury? **(Do not count the day(s) spent in bed)**

_____ **DAYS** during the past month

15. Are you unable to do certain kinds or amounts of work, housework, or schoolwork because of your health?

(Circle one)

YES, for less than 3 months 1
YES, for 3 or more months 2
NO, my health does not limit me this way 0

16. Does your health keep you from working at a job, doing work around the house, or going to school?

(Circle one)

YES, for less than 3 months 1
YES, for 3 or more months 2
NO, my health does not limit me this way 0

17. How do you feel about your own health?

(Circle one)

VERY SATISFIED 5
SATISFIED 4
NOT SURE 3
DISSATISFIED 2
VERY DISSATISFIED 1

WELL-BEING

These next questions ask about how you feel and how things have been with you **during the past month.** For each question, please circle the number for the one answer that comes closest to the way you have been feeling.

DURING THE PAST MONTH, HOW MUCH OF THE TIME:	ALL OF THE TIME	MOST OF THE TIME	A GOOD BIT OF THE TIME	SOME OF THE TIME	A LITTLE OF THE TIME	NONE OF THE TIME
18. Have you been a very nervous person?	1	2	3	4	5	6
19. Have you felt calm and peaceful?	1	2	3	4	5	6
20. Have you felt downhearted and blue?	1	2	3	4	5	6
21. Were you a happy person?	1	2	3	4	5	6
22. Did you feel so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
23. Did you isolate yourself from people around you?	1	2	3	4	5	6
24. Were you affectionate toward others?	1	2	3	4	5	6
25. Did you act irritable toward those around you?	1	2	3	4	5	6
26. Did you make unreasonable demands on your family and friends?	1	2	3	4	5	6
27. Did you get along well with other people?	1	2	3	4	5	6

SOCIAL ACTIVITIES

28. About how many **close** friends do you have — people you feel at ease with and can talk with about what is on your mind? **(You may include relatives.)**

(Enter number on line:)

_____ **CLOSE FRIENDS AND RELATIVES.**

29. During the past month, about how often did you get together with friends or relatives, like going out together, visiting in each other's homes, or talking on the telephone?

	(Circle one)
EVERY DAY	6
SEVERAL TIMES A WEEK	5
ABOUT ONCE A WEEK	4
2 OR 3 TIMES DURING THE MONTH	3
ABOUT ONCE A MONTH	2
NOT AT ALL	1

30. During the past month, how satisfied were you with your sexual relationships?

	(Circle one)
VERY SATISFIED	5
SATISFIED	4
NOT SURE	3
DISSATISFIED	2
VERY DISSATISFIED	1
DID NOT HAVE ANY SEXUAL RELATIONSHIPS	0

EMPLOYMENT

The next question concerns your present working situation **other than managing your home.**

31. Which of the following statements best describes your work situation **during the past month?**

(Circle one)

WORKING FULL TIME	1	Go to Question 32 Below
WORKING PART-TIME	2	
UNEMPLOYED, LOOKING FOR WORK	3	Go to Next Page
UNEMPLOYED BECAUSE OF MY HEALTH	4	
RETIRED BECAUSE OF MY HEALTH	5	
RETIRED FOR SOME OTHER REASON	6	
OTHER:	7	

These next questions ask about how **your health** affects your work.

DURING THE PAST MONTH, HOW MUCH OF THE TIME DID YOU:	ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	NONE OF THE TIME
32. Do as much work as others in similar jobs?	1	2	3	4
33. Work for short periods of time or take frequent rests because of your health?	1	2	3	4
34. Work your regular number of hours?	1	2	3	4
35. Do your job as carefully and accurately as others with similar jobs?	1	2	3	4
36. Work at your usual job, but with some changes because of your health (for example, use special equipment, trade tasks with other workers)?	1	2	3	4
37. Fear losing your job because of your health?	1	2	3	4

Thank you very much for taking the time to complete this questionnaire. We appreciate your cooperation. If you have anything else you wish to add, please write in the space below. Thank you.

GENERAL HEALTH QUESTIONNAIRE

The General Health Questionnaire (GHQ) is a self-administered screening test, designed to identify short-term changes in mental health (depression, anxiety, social dysfunction and somatic symptoms). It is a pure state measure, responding to how much a subject feels that their present state "over the past few weeks" is unlike their usual state. It does not make clinical diagnoses and should not be used to measure long-standing attributes.

The GHQ focuses on the client's ability to carry out "normal" functions and the appearance of any new disturbing phenomena. Designed for use by doctors, psychiatrists and researchers, the GHQ is ideal for use in community and non-psychiatric settings and has four different versions: GHQ-60: the fully detailed 60-item questionnaire, GHQ-30: a short form without items relating to physical illness, GHQ-28: a 28 item scaled version - assesses somantic symptoms, anxiety and insomnia, social dysfunction and severe depression, and GHQ-12: a quick, reliable and sensitive short form - ideal for research studies

Abbreviated Name: GHQ
Author(s): D. Goldberg
Purpose: Screening instrument to detect psychiatric disorders in community settings and non-psychiatric clinical settings, such as primary care or general practice.
Population: Adult
Age Range : 18+ years
Type of Instrument: Symptom/functioning
Mode of Administration:

Rater:	Self-administered
Time required:	GHQ-30: 3-4 min / GHQ-60: 6-8 min
Response Options:	Likert scale
Scoring:	Global score
	Scores by dimension (in the GHQ-28 only)
Score Direction:	Lower scores show better QoL

Number of Items: Different versions have been developed: GHQ-12, GHQ-28, GHQ-30 and GHQ-60
Original Language: English
Existing Translations :
GHQ-12 : Arabic, Cantonese, French, German, Gujarati, Mandarin, Nepalese, Portuguese, Punjabi, Russian, Serbo-Croat, Sorani, Swedish, Turkish, Urdu
GHQ-28 : Albanian, Arabic, Cantonese, French, German, Greek, Gujarati, Mandarin, Nepalese, Punjabi, Russian, Serbian / Serbo-Croat, Sorani, Turkish, Urdu
GHQ-30 : Arabic, Bengali, French, Gujarati, Punjabi, Urdu
GHQ-60 : Cantonese, Mandarin

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Contact for information and permission to use:

Tim Cornford,
NferNelson Publishing Company,
The Chiswick Centre, 414 Chiswick High Road
London W4 5TF, UK.
Tel : +44 (0)20 8996 8457
Website: www.nfer-nelson.co.uk
E-mail: tim.cornford@nfer-nelson.co.uk

Dimensions covered by the questionnaire :

- Somatic symptoms (7 items)
- Anxiety and insomnia (7 items)
- Social dysfunction (7 items)
- Severe depression (7 items)

Key References:

1. Goldberg DP. The detection of psychiatric illness by questionnaire. London, Oxford University Press, 1972.
2. Goldberg DP et al. Manual of the General Health Questionnaire. Windsor, England, NFER Publishing, 1978
3. Goldberg DP et al. A scaled version of the General Health Questionnaire. Psychol Med 1979;9:139-145
4. Vieweg BW, and Hedlund JL . The General Health Questionnaire (GHQ): A comprehensive review. Journal of Operational Psychiatry 1983; 14(2), 74-81.
5. Goldberg DP, Oldehinkel T, Ormel J. Why GHQ threshold varies from one place to another. PsycholMed 1998 ;28(4):915-21.

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General Health Questionnaire-28 Item Version (GHQ-28) (only for sample and your preview)

Please read this carefully. This refers to how your health has been in general over the past few weeks. This applies only to present and recent complaints not those that you had in the past. It is important that you try to answer ALL the questions.

A:Somatic Complaints				
Have you recently:	0 points	1 point	2 points	3 points
(A1) been feeling perfectly well and in good health?	better than usual	same as usual	worse than usual	much worse than usual
(A2) been feeling in need of a good tonic?	not at all	no more than usual	rather more than usual	much more than usual
(A3) been feeling run down and out of sorts?	not at all	no more than usual	rather more than usual	much more than usual
(A4) felt that you are ill?	not at all	no more than usual	rather more than usual	much more than usual
(A5) been getting any pains in your head?	not at all	no more than usual	rather more than usual	much more than usual
(A6) been getting a feeling of tightness or pressure in your head?	not at all	no more than usual	rather more than usual	much more than usual
(A7) been having hot or cold spells?	not at all	no more than usual	rather more than usual	much more than usual

B:Anxiety and Insomnia				
Have you recently:	0 points	1 point	2 points	3 points
(B1) lost much sleep over worry?	not at all	no more than usual	rather more than usual	much more than usual
(B2) had difficulty in staying asleep once your are off?)	not at all	no more than usual	rather more than usual	much more than usual
(B3) felt constantly under strain?	not at all	no more than usual	rather more than usual	much more than usual
(B4) been getting edgy and bad-tempered?	not at all	no more than usual	rather more than usual	much more than usual
(B5) been getting scared or panicky for no good reason?	not at all	no more than usual	rather more than usual	much more than usual
(B6) found everything getting on top of you?	not at all	no more than usual	rather more than usual	much more than usual
(B7) been feeling nervous and strung-up all the time?	not at all	no more than usual	rather more than usual	much more than usual

C: Social Dysfunction				
Have you recently:	0 points	1 point	2 points	3 points
(C1) been managing to keep yourself busy and occupied?	more so than usual	same as usual	rather less than usual	much less than usual
(C2) been taking longer over the things you do?	quicker than usual	same as usual	longer than usual	much longer than usual
(C3) felt on the whole you were doing things well?	better than usual	about the same	less well than usual	much less well than usual
(C4) been satisfied with the way you've carried out your task?	more satisfied	about the same	less satisfied than usual	much less satisfied than usual
(C5) felt that you are playing a useful part in things?	more so than usual	about the same	less useful than usual	much less useful than usual
(C6) felt capable of making decisions about things?	more so than usual	about the same	less so than usual	much less capable
(C7) been able to enjoy your normal day-to-day activities?	more so than usual	same as usual	rather less than usual	much more than usual

D: Severe Depression				
Have you recently:	0 points	1 point	2 points	3 points
(D1) been thinking of yourself as a worthless person?	not at all	no more than usual	rather more than usual	much more than usual
(D2) felt that life is entirely hopeless?	not at all	no more than usual	rather more than usual	much more than usual
(D3) felt that life isn't worth living?	not at all	no more than usual	rather more than usual	much more than usual
(D4) thought of the possibility that you might do away with yourself?	definitely not	I don't think so	has crossed my mind	definitely has
(D5) found at times you couldn't do anything because your nerves were too bad?	not at all	no more than usual	rather more than usual	much more than usual
(D6) found yourself wishing you were dead and away from it all?	not at all	no more than usual	rather more than usual	much more than usual
(D7) found that the idea of taking your own life kept coming into your mind?	definitely not	I don't think so	has crossed my mind	definitely has

score for A scale =

= SUM (points for 7 questions in part A)

score for B scale =

= SUM (points for 7 questions in part B)

score for C scale =

= SUM (points for 7 questions in part C)

score for D scale =

= SUM (points for 7 questions in part D)

total score =

= score for all 4 scales

GLASGOW HEALTH STATUS QUESTIONNAIRES

Glasgow Benefit Inventory (GBI) measures the change in health status produced by surgical interventions (here, "health status" is the general perception of well-being, including total psychological, social, and physical well being). Glasgow Health Status Inventory (GHSI) assesses health state, by measuring the effect of a health problem on the quality of life of a person. It allows cross-comparison among many health conditions, among different health interventions, and among demographic and cultural subgroups.

The GBI is a post-intervention questionnaire which assesses the interventions effects on the health status of the patients. The GHSI can be used at any point in time and measures the general quality of life the person experiences and how health problems affect this. While the GBI is maximally sensitive to an change in health status brought about by a specific event (e.g. an operation), the GHSI gives a general measure of the health status of the person at any specific time.

Both questionnaires contain 18 questions which can be completed either in an interview or filled-in by the patient. The interview takes about 10 minutes to complete, while self-administration would be completed in about 5 minutes.

Abbreviated Name: GHSQ/GBI&GHSI
(Glasgow Benefit Inventory&Glasgow Health Status Inventory)
Author(s): Ken Robinson, Stuart Gatehouse and George G. Browning
Purpose:
GBI: To measure the change in health status produced by surgical interventions (change questionnaire)
GHSI: To measure the effect of a health problem on the quality of life of a person and allows cross-comparison among many health conditions, among different health intervention, and among demographic and cultural subgroups (state questionnaire)
Population: Adult
Age Range: 18 and over
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-/ Interviewer-administered
Time required:	5-10 minutes
Response Options:	Likert scale
Scoring:	Global score: Min score: - 100 (GBI scores)/ Max score:+ 100 Min score : 0 (GHSI scores) / Max score:100 Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 18
Original Language: English
Existing Translations: Danish, Dutch, French, German, Italian, Spanish, Swedish

Contact for information and permission to use:

MRC Institute of Hearing Research
Scottish Section
North Glasgow University Hospitals NHS Trust
Glasgow Royal Infirmary
Queen Elizabeth Building
16 Alexandra Parade
Glasgow G31 2ER, UK
Phone: 0141 211 4695
Fax: 0141 552 8411
Email: stuart@ihr.gla.ac.uk

Dimensions covered by the questionnaire :

- General subscale (12 items)
- Social support subscale (3 items)
- Physical health subscale (3 items)

Key References:

1. Robinson K, Gatehouse S, Browning GG. Measuring patient benefit from otorhinolaryngological surgery and therapy. Ann Otol Rhinol Laryngol 1996;105(6):415-22

The Glasgow Benefit Inventory (GBI) is a measure of patient benefit developed especially for otorhinolaryngological (ORL) interventions. Patient benefit is the change in health status resulting from health care intervention. The GBI was developed to be patient-oriented, to be maximally sensitive to ORL interventions, and to provide a common metric to compare benefit across different interventions. The GBI is an 18-item, postintervention questionnaire intended to be given to patients to fill in at home or in the outpatient clinic. In the first part of the paper, five different ORL interventions were retrospectively studied: middle ear surgery to improve hearing, provision of a cochlear implant, middle ear surgery to eradicate ear activity, rhinoplasty, and tonsillectomy. A criterion that was specific to the intervention was selected for each study, so that the patient outcome could be classified as above and below criterion. In all five interventions, the GBI was found to discriminate between above- and below-criterion outcomes. The second part of the paper reports on the results and implications of a factor analysis of patient responses. The factor structure was robust across the study, and so led to the construction of subscales. These subscales yield a profile score that provides information on the different types of patient benefit resulting from ORL interventions. The GBI is sensitive to the different ORL interventions, yet is sufficiently general to enable comparison between each pair of interventions. It provides a profile score, which enables further breakdown of results. As it provides a patient-oriented common metric, it is anticipated that the GBI will assist audit, research, and health policy planning.

THE

GLASGOW

HEALTH STATUS

QUESTIONNAIRES

MANUAL

1999

Introduction

The overall success of any medical or surgical intervention cannot be obtained from measures of technical success alone and changes in patient quality of life resulting from the intervention must also be considered. While there are existing measures of health status and patient satisfaction, none of these measures were generated specifically for otorhinolaryngology, and their sensitivity to otorhinolaryngological (ORL) interventions is poor when compared to other interventions, largely due to their poor sensitivity to nonacute disorders such as are generally seen in otorhinolaryngology. It was, therefore, decided to generate two health status questionnaires, a state questionnaire, the Glasgow Health Status Inventory (GHSI), and a change questionnaire, the Glasgow Benefit Inventory (GBI), which would be specifically sensitive to ORL health problems and interventions and also generalisable across different ORL health problems and interventions. The questions are independent of any specific intervention/health condition and the subject of the questions remains constant. Each of the questions addresses an aspect of health-related quality of life which is not dependent on the disease of interest or the context of the intervention. However, to improve sensitivity, the text is altered for each question to allow focusing on to the intervention or health condition of interest. The questions are thus generic in nature but referenced to a temporal event (intervention) in the GBI or condition in the GHSI.

The change questionnaire (GBI) measures the change in health status produced by surgical interventions. For this measure, the definition of health status is the general perception of well-being, including total psychological, social and physical well-being. Given that maximal sensitivity to change was critical, it was decided to ask directly about the change in health status resulting from surgery, rather than take pre- and post- operative measures and subtract one from the other. The accompanying paper shows the findings of a study investigating the sensitivity of the GBI to the change in health status resulting from 5 different ORL interventions.

The state questionnaire (GHSI) measures the effect of a health problem on the quality of life of a person and allows cross-comparison among many health conditions, among different health interventions, and among demographic and cultural subgroups.

The GBI is a post-intervention questionnaire which assesses the intervention's effects on the health status of the patient. The GHSI can be used at any point in time and measures the general quality of life the person experiences and how health problems affect this. While the GBI is maximally sensitive to a change in health status brought about by a specific event (e.g. an operation), the GHSI gives a general measure of the health status of the person at any specific time.

Both questionnaires contain 18 questions which can be completed either in an interview or filled in by the patient. The interview takes about 10 minutes to complete, while self-administration would be completed in about 5 minutes. However, we advise using the interview technique wherever possible as this leads to more complete and comparable datasets.

GBI - Glasgow Benefit Inventory

The GBI contains 18 change in health status questions which assess how the intervention has altered the quality of life of the person. The GBI is easily adapted to be used for different interventions. Before use, the GBI must be adapted so that the intervention of interest is specified. This is done by replacing the words in italics (*operation/intervention)* in each question with the intervention of interest. See the examples below.

Example of all-purpose GBI question:

Since your *operation/intervention**, have you found it easier or harder to deal with company?

Examples of focused GBI questions :

Since your operation, have you found it easier or harder to deal with company?

Since you received your hearing aid, have you found it easier or harder to deal with company?

Since your speech therapy, have you found it easier or harder to deal with company?

Scoring

The response to each question is based on a five-point Likert scale ranging from a large deterioration in health status through to a large improvement in health status, (see example below).

1. Has the result of the *operation/intervention affected the things you do?**

Much worse better	A little or somewhat	No change	A little or somewhat	Much better	worse
1	2	3	4	5	

To help control for response bias, half of the questions have the answers ranging from a large improvement on the left to a large deterioration on the right while the other half range the other way. It is advisable to remove these numbers when asking the person to fill out questionnaire on their own to restrict response biases. The GBI questionnaire is scored into a total score and also 3 subscales :- a general subscale (12 questions), a social support subscale (3 questions), and a physical health subscale (3 questions). All these scores range from –100 to +100.

Total Score
- Sum all the responses (Qu. 1-18)
- Divide by 18 (to obtain an average response score)
- Subtract 3 from the average response score
- Multiply by 50.

General Subscale Score
- Sum 12 of the responses (Qu. 1,2,3,4,5,6,9,10,14,16,17 and 18)
- Divide by 12 (to obtain an average response score)
- Subtract 3 from the average response score
- Multiply by 50.

Social Support Score
- Sum 3 of the responses (Qu. 7,11,15)
- Divide by 3(to obtain an average response score)
- Subtract 3 from the average response score
- Multiply by 50.

Physical Health Score
- Sum 3 of the responses (Qu. 8,12,13)
- Divide by 3(to obtain an average response score)
- Subtract 3 from the average response score
- Multiply by 50.

The GBI questionnaire (generic form)

1.	**Has the result of the *operation/intervention** affected the things you do?**				
	Much worse 1	A little or somewhat worse 2	No change 3	A little or somewhat better 4	Much better 5
2.	**Have the results of the *operation/intervention** made your overall life better or worse?**				
	Much better 5	A little or somewhat better 4	No change 3	A little or somewhat worse 2	Much worse 1
3.	**Since your *operation/intervention**, have you felt more or less optimistic about the future?**				
	Much more optimistic 5	More optimistic 4	No change 3	Less optimistic 2	Much less optimistic 1
4.	**Since your *operation/intervention**, do you feel more or less embarrassed when with a group of people?**				
	Much more embarrassed 1	More embarrassed 2	No change 3	Less embarrassed 4	Much less embarrassed 5
5.	**Since your *operation/intervention**, do you have more or less self-confidence?**				
	Much more self-confidence 5	More self-confidence 4	No change 3	Less self-confidence 2	Much less self-confidence 1
6.	**Since your *operation/intervention**, have you found it easier or harder to deal with company?**				
	Much easier 5	Easier 4	No change 3	Harder 2	Much harder 1
7.	**Since your *operation/intervention**, do you feel that you have more or less support from your friends?**				
	Much more support 5	More support 4	No change 3	Less support 2	Much less support 1
8.	**Have you been to your family doctor, for any reason, more or less often, since your *operation/intervention**?**				
	Much more often 1	More often 2	No change 3	Less often 4	Much less often 5
9.	**Since your *operation/intervention**, do you feel more or less confident about job opportunities?**				
	Much more confident 5	More confident 4	No change 3	Less confident 2	Much less confident 1
10.	**Since your *operation/intervention**, do you feel more or less self-conscious?**				
	Much more self-conscious 1	More self-conscious 2	No change 3	Less self-conscious 4	Much less self conscious 5
11.	**Since your *operation/intervention**, are there more or fewer people who really care about you?**				
	Many more people 5	More people 4	No change 3	Fewer people 2	Many fewer people 1
12.	**Since you had the *operation/intervention**, do you catch colds or infections more or less often?**				
	Much more often 1	More often 2	No change 3	Less often 4	Much less often 5
13.	**Have you had to take more or less medicine for any reason, since your *operation/intervention**?**				
	Much more medicine 1	More medicine 2	No change 3	Less medicine 4	Much less medicine 5

14. Since your *operation/intervention, do you feel better or worse about yourself?**				
Much better 5	Better 4	No change 3	Worse 2	Much worse 1
15. Since your *operation/intervention, do you feel that you have had more or less support from your family?**				
Much more support 5	More support 4	No change 3	Less support 2	Much less support 1
16. Since your *operation/intervention, are you more or less inconvenienced by your *health** problem?**				
Much more inconvenienced 1	More inconvenienced 2	No change 3	Less inconvenienced 4	Much less inconvenienced 5
17. Since your *operation/intervention, have you been able to participate in more or fewer social activities?**				
Many more activities 5	More activities 4	No change 3	Fewer activities 2	Many fewer activities 1
18. Since your *operation/intervention, have you been more or less inclined to withdraw from social situations?**				
Much more inclined 1	More inclined 2	No change 3	Less inclined 4	Much less inclined 5

Specific examples of GBI questionnaire items

(i) Otological surgery

1. Has the result of your ear operation affected the things you do?
2. Have the results of your ear operation made your overall life better or worse?
3. Since your ear operation have you felt more or less optimistic about the future?
4. Since your ear operation do you feel more or less embarrassed when with a group of people?
5. Since your ear operation do you have more or less self-confidence?
6. Since your ear operation have you found it easier or harder to deal with company?
7. Since your ear operation do you feel that you have more or less support from your friends?
8. Have you been to your family doctor, for any reason, more or less often, since your ear operation?
9. Since your ear operation do you feel more or less confident about job opportunities?
10. Since your ear operation do you feel more or less self-conscious?
11. Since your ear operation are there more or fewer people who really care about you?
12. Since you had your ear operation do you catch colds or infections more or less often?
13. Have you had to take more or less medicine for any reason, since your ear operation?
14. Since your ear operation do you feel better or worse about yourself?
15. Since your ear operation do you feel that you have had more or less support from your family?
16. Since your ear operation are you more or less inconvenienced by your health problem?
17. Since your ear operation have you been able to participate in more or fewer social activities?
18. Since your ear operation have you been more or less inclined to withdraw from social situations?

(ii) Nasal surgery

1. Has the result of your nose operation affected the things you do?
2. Have the results of your nose operation made your overall life better or worse?
3. Since your nose operation have you felt more or less optimistic about the future?
4. Since your nose operation do you feel more or less embarrassed when with a group of people?
5. Since your nose operation do you have more or less self-confidence?
6. Since your nose operation have you found it easier or harder to deal with company?
7. Since your nose operation do you feel that you have more or less support from your friends?
8. Have you been to your family doctor, for any reason, more or less often, since your nose operation?
9. Since your nose operation do you feel more or less confident about job opportunities?
10. Since your nose operation do you feel more or less self-conscious?
11. Since your nose operation are there more or fewer people who really care about you?
12. Since you had your nose operation do you catch colds or infections more or less often?
13. Have you had to take more or less medicine for any reason, since your nose operation?
14. Since your nose operation do you feel better or worse about yourself?
15. Since your nose operation do you feel that you have had more or less support from your family?
16. Since your nose operation are you more or less inconvenienced by your health problem?
17. Since your nose operation have you been able to participate in more or fewer social activities?
18. Since your nose operation have you been more or less inclined to withdraw from social situations?

(iii) Throat surgery

1. Has the result of your throat operation affected the things you do?
2. Have the results of your throat operation made your overall life better or worse?
3. Since your throat operation have you felt more or less optimistic about the future?
4. Since your throat operation do you feel more or less embarrassed when with a group of people?
5. Since your throat operation do you have more or less self-confidence?
6. Since your throat operation have you found it easier or harder to deal with company?
7. Since your throat operation do you feel that you have more or less support from your friends?
8. Have you been to your family doctor, for any reason, more or less often, since your throat operation?
9. Since your throat operation do you feel more or less confident about job opportunities?
10. Since your throat operation do you feel more or less self-conscious?
11. Since your throat operation are there more or fewer people who really care about you?
12. Since you had your throat operation do you catch colds or infections more or less often?
13. Have you had to take more or less medicine for any reason, since your throat operation?
14. Since your throat operation do you feel better or worse about yourself?
15. Since your throat operation do you feel that you have had more or less support from your family?
16. Since your throat operation are you more or less inconvenienced by your health problem?
17. Since your throat operation have you been able to participate in more or fewer social activities?
18. Since your throat operation have you been more or less inclined to withdraw from social situations?

(iv) Provision of a hearing aid

1. Has the result of getting a hearing aid affected the things you do?
2. Has the result of getting a hearing aid made your overall life better or worse?
3. Since getting your hearing aid have you felt more or less optimistic about the future?
4. Since getting your hearing aid do you feel more or less embarrassed when with a group of people?
5. Since getting your hearing aid do you have more or less self-confidence?
6. Since getting your hearing aid have you found it easier or harder to deal with company?
7. Since getting your hearing aid do you feel that you have more or less support from your friends?
8. Have you been to your family doctor, for any reason, more or less often, since getting your hearing aid?
9. Since getting your hearing aid do you feel more or less confident about job opportunities?
10. Since getting your hearing aid do you feel more or less self-conscious?
11. Since getting your hearing aid are there more or fewer people who really care about you?
12. Since getting your hearing aid do you catch colds or infections more or less often?
13. Have you had to take more or less medicine for any reason, since getting your hearing aid?
14. Since getting your hearing aid do you feel better or worse about yourself?
15. Since getting your hearing aid do you feel that you have had more or less support from your family?
16. Since getting your hearing aid are you more or less inconvenienced by your health* problem?
17. Since getting your hearing aid have you been able to participate in more or fewer social activities?
18. Since getting your hearing aid have you been more or less inclined to withdraw from social situations?

(v) Speech therapy

1. Has the result of your speech therapy affected the things you do?
2. Have the results of your speech therapy made your overall life better or worse?
3. Since your speech therapy have you felt more or less optimistic about the future?
4. Since your speech therapy do you feel more or less embarrassed when with a group of people?
5. Since your speech therapy do you have more or less self-confidence?
6. Since your speech therapy have you found it easier or harder to deal with company?
7. Since your speech therapy do you feel that you have more or less support from your friends?
8. Have you been to your family doctor, for any reason, more or less often, since your speech therapy?
9. Since your speech therapy do you feel more or less confident about job opportunities?
10. Since your speech therapy do you feel more or less self-conscious?
11. Since your speech therapy are there more or fewer people who really care about you?
12. Since you had your speech therapy do you catch colds or infections more or less often?
13. Have you had to take more or less medicine for any reason, since your speech therapy?
14. Since your speech therapy do you feel better or worse about yourself?
15. Since your speech therapy do you feel that you have had more or less support from your family?
16. Since your speech therapy are you more or less inconvenienced by your health problem?
17. Since your speech therapy have you been able to participate in more or fewer social activities?
18. Since your speech therapy have you been more or less inclined to withdraw from social situations?

(vi) Dizziness therapy

1. Has the result of your treatment for dizziness affected the things you do?
2. Have the results of your treatment for dizziness made your overall life better or worse?
3. Since your treatment for dizziness have you felt more or less optimistic about the future?
4. Since your treatment for dizziness do you feel more or less embarrassed when with a group of people?
5. Since your treatment for dizziness do you have more or less self-confidence?
6. Since your treatment for dizziness have you found it easier or harder to deal with company?
7. Since your treatment for dizziness do you feel that you have more or less support from your friends?
8. Have you been to your family doctor, for any reason, more or less often, since your treatment for dizziness?
9. Since your treatment for dizziness do you feel more or less confident about job opportunities?
10. Since your treatment for dizziness do you feel more or less self-conscious?
11. Since your treatment for dizziness are there more or fewer people who really care about you?
12. Since you had your treatment for dizziness do you catch colds or infections more or less often?
13. Have you had to take more or less medicine for any reason, since your treatment for dizziness?
14. Since your treatment for dizziness do you feel better or worse about yourself?
15. Since your treatment for dizziness do you feel that you have had more or less support from your family?
16. Since your treatment for dizziness are you more or less inconvenienced by your health problem?
17. Since your treatment for dizziness have you been able to participate in more or fewer social activities?
18. Since your treatment for dizziness have you been more or less inclined to withdraw from social situations?

GHSI - Glasgow Health Status Inventory

The GHSI contains 18 health status questions which ask specific questions about how the health problem has affected their quality of life at the time the GHSI is completed.

The GHSI is shown as an all-purpose questionnaire. It is adapted to focus on different health problems. Before use, the GHSI must be adapted so that the health condition of interest is specified. This is done by replacing the words in italics (*health problem)* in each question into the intervention of interest. See the examples below.

Example of an all-purpose question
How often does any difficulty with your *health problem* make you feel self-conscious?
Example of focused question
How often does any difficulty with your ear problem make you feel self-conscious?
When your nose is blocked do you feel self-conscious?

Scoring

The response to each question is based on a five-point Likert scale ranging from high health status through to low health status, (see example below).

4. As a result of your *health problem*, how often do you feel embarrassment when with a group of people?				
Frequently or all of the time	About half the time	Occasionally	Rarely	Never
1	2	3	4	5

To help control for response bias, half of the questions have the answers ranging from a large effect on the left to a zero effect on the right while the other half range the other way. It is advisable to remove these numbers when asking the person to fill out questionnaire on their own to restrict response biases. The GHSI questionnaire is scored into a total score and also 3 subscales:- a general subscale (12 questions), a social support subscale (3 questions), and a physical health subscale (3 questions). All these scores range from 0 to +100, with 0 corresponding to the poorest health state and 100 the best.

Total Score
- Sum all the responses (Qu. 1-18)
- Divide by 18 (to obtain an average response score)
- Subtract 1 from the average response score
- Multiply by 25.

General Subscale Score
- Sum 12 of the responses (Qu. 1,2,3,4,5,6,9,10,14,16,17 and 18)
- Divide by 12 (to obtain an average response score)
- Subtract 1 from the average response score
- Multiply by 25.

Social Support Score
- Sum 3 of the responses (Qu. 7,11,15)
- Divide by 3(to obtain an average response score)
- Subtract 1 from the average response score
- Multiply by 25.

Physical Health Score
- Sum 3 of the responses (Qu. 8,12,13)
- Divide by 3(to obtain an average response score)
- Subtract 1 from the average response score
- Multiply by 25.

The GHSI questionnaire (generic form)

1.	**How often does your *health problem* affect the things you do?**				
	Frequently or all of the time	About half the time	Occasionally	Rarely	Never
	1	2	3	4	5
2.	**How much does your *health problem* affect your overall life?**				
	Not at all affected	Very slightly affected	Slightly affected	Moderately affected	Greatly affected
	5	4	3	2	1
3.	**Which of the following statements best describes your view of the future?**				
	Optimistic	A little optimistic	Can't decide	A little pessimistic	Pessimistic
	5	4	3	2	1
4.	**As a result of your *health problem*, how often do you feel embarrassment when with a group of people?**				
	Frequently or all of the time	About half the time	Occasionally	Rarely	Never
	1	2	3	4	5
5.	**Is your self-confidence affected by your *health problem*?**				
	Not at all affected	Very slightly affected	Slightly affected	Moderately affected	Greatly affected
	5	4	3	2	1
6.	**How often does any difficulty with your *health problem* affect how you deal with company?**				
	Never	Rarely	Occasionally	About half the time	Frequently or all of the time
	5	4	3	2	1
7.	**How much support do you have from your friends?**				
	A great deal of support	A good deal of support	Quite a lot of support	Some support	Little or no support
	5	4	3	2	1
8.	**How often do you consult your family doctor for any reason?**				
	Seven or more times a year	Five or six times a year	Three or four times a year	Once or twice a year	Never
	1	2	3	4	5
9.	**How often does any difficulty with your *health problem* affect how confident you are about job opportunities?**				
	Never	Rarely	Occasionally	About half the time	Frequently or all of the time
	5	4	3	2	1
10.	**How often does any difficulty with your *health problem* make you feel self-conscious?**				
	Frequently or all of the time	About half the time	Occasionally	Rarely	Never
	1	2	3	4	5
11.	**How many people really care about you?**				
	More than six people	Five or six people	Three or four people	One or two people	None
	5	4	3	2	1
12.	**If there is a cold or infection going around, how often do you usually catch it?**				
	Frequently or all of the time	About half the time	Occasionally	Rarely	Never
	1	2	3	4	5
13.	**How often do you have to take medicine for any reason**				
	Frequently or all of the time	About half the time	Occasionally	Rarely	Never
	1	2	3	4	5

14. Does any difficulty with your *health problem* affect the way you feel about yourself?				
Feelings never affected 1	Feelings very slightly affected 2	Feelings slightly affected 3	Feelings moderately affected 4	Feelings greatly affected 5
15. How much support do you have from your family				
A great deal of support 5	A good deal of support 4	Quite a lot of support 3	Some support 2	Little or no support 1
16. How often are you inconvenienced by your *health problem*?				
Daily 5	One or two times a week 4	One or two times a month 3	Less than 6 times a year 4	Never 5
17. How often do you participate in social activities?				
More than three times a day 1	Once or twice a day 2	Once or twice a week 3	Once or twice a month 4	Less than 3 times a month 5
18. How often do you feel inclined to withdraw from social situations?				
Frequently or all of the time 1	About half the time 2	Occasionally 3	Rarely 4	Never 5

Specific examples of GHSI questions

(i) Ear Problem

1. How often does any problem with your ears affect the things you do?
2. How much does any problem with your ears affect your overall life?
3. Which of the following statements best describes your view of the future?
4. As a result of any problem with your ears, how often do you feel embarrassment when with a group of people?
5. Is your self-confidence affected by any problem with your ears?
6. How often does any problem with your ears affect how you deal with company?
7. How much support do you have from your friends?
8. How often do you consult your family doctor for any reason?
9. How often does any problem with your ears affect how confident you are about job opportunities?
10. How often does any problem with your ears make you feel self-conscious?
11. How many people really care about you?
12. If there is a cold or infection going around, how often do you usually catch it?
13. How often do you have to take medicine for any reason?
14. Does any problem with your ears affect the way you feel about yourself?
15. How much support do you have from your family?
16. How often are you inconvenienced by a problem with your ears?
17. How often do you participate in social activities?
18. How often do you feel inclined to withdraw from social situations?

(ii) Nose Problem

1. How often do any problems with your nose affect the things you do?
2. How much do any problems with your nose affect your overall life?
3. Which of the following statements best describes your view of the future?
4. As a result of any problems with your nose, how often do you feel embarrassment when with a group of people?
5. Is your self-confidence affected by any problems with your nose?
6. How often do any problems with your nose affect how you deal with company?
7. How much support do you have from your friends?
8. How often do you consult your family doctor for any reason?
9. How often do any problems with your nose affect how confident you are about job opportunities?
10. How often do any problems with your nose make you feel self-conscious?
11. How many people really care about you?
12. If there is a cold or infection going around, how often do you usually catch it?
13. How often do you have to take medicine for any reason?
14. Do any problems with your nose affect the way you feel about yourself?
15. How much support do you have from your family?
16. How often are you inconvenienced by any problems with your nose?
17. How often do you participate in social activities?
18. How often do you feel inclined to withdraw from social situations?

(iii) Throat Problem

1. How often do any problems with your throat affect the things you do?
2. How much do any problems with your throat affect your overall life?
3. Which of the following statements best describes your view of the future?
4. As a result of any problems with your throat, how often do you feel embarrassment when with a group of people?
5. Is your self-confidence affected by any problems with your throat?
6. How often do any problems with your throat affect how you deal with company?
7. How much support do you have from your friends?
8. How often do you consult your family doctor for any reason?
9. How often do any problems with your throat affect how confident you are about job opportunities?
10. How often do any problems with your throat make you feel self-conscious?
11. How many people really care about you?
12. If there is a cold or infection going around, how often do you usually catch it?
13. How often do you have to take medicine for any reason?
14. Do any problems with your throat affect the way you feel about yourself?
15. How much support do you have from your family?
16. How often are you inconvenienced by any problems with your throat?
17. How often do you participate in social activities?
18. How often do you feel inclined to withdraw from social situations?

(iv) Hearing Problem

1. How often do any problems with your hearing affect the things you do?
2. How much do any problems with your hearing affect your overall life?
3. Which of the following statements best describes your view of the future?
4. As a result of any problems with your hearing, how often do you feel embarrassment when with a group of people?
5. Is your self-confidence affected by any problems with your hearing?
6. How often do any problems with your hearing affect how you deal with company?
7. How much support do you have from your friends?
8. How often do you consult your family doctor for any reason?
9. How often do any problems with your hearing affect how confident you are about job opportunities?
10. How often do any problems with your hearing make you feel self-conscious?
11. How many people really care about you?
12. If there is a cold or infection going around, how often do you usually catch it?
13. How often do you have to take medicine for any reason?
14. Do any problems with your hearing affect the way you feel about yourself?
15. How much support do you have from your family?
16. How often are you inconvenienced by any problems with your hearing?
17. How often do you participate in social activities?
18. How often do you feel inclined to withdraw from social situations?

(v) Voice Problem

1. How often do any problems with your voice affect the things you do?
2. How much do any problems with your voice affect your overall life?
3. Which of the following statements best describes your view of the future?
4. As a result of any problems with your voice, how often do you feel embarrassment when with a group of people?
5. Is your self-confidence affected by any problems with your voice?
6. How often do any problems with your voice affect how you deal with company?
7. How much support do you have from your friends?
8. How often do you consult your family doctor for any reason?
9. How often do any problems with your voice affect how confident you are about job opportunities?
10. How often do any problems with your voice make you feel self-conscious?
11. How many people really care about you?
12. If there is a cold or infection going around, how often do you usually catch it?
13. How often do you have to take medicine for any reason?
14. Do any problems with your voice affect the way you feel about yourself?
15. How much support do you have from your family?
16. How often are you inconvenienced by any problems with your voice?
17. How often do you participate in social activities?
18. How often do you feel inclined to withdraw from social situations?

(vi) Balance Problem

1. How often do any problems with your balance affect the things you do?
2. How much do any problems with your balance affect your overall life?
3. Which of the following statements best describes your view of the future?
4. As a result of any problems with your balance, how often do you feel embarrassment when with a group of people?
5. Is your self-confidence affected by any problems with your balance?
6. How often do any problems with your balance affect how you deal with company?
7. How much support do you have from your friends?
8. How often do you consult your family doctor for any reason?
9. How often do any problems with your balance affect how confident you are about job opportunities?
10. How often do any problems with your balance make you feel self-conscious?
11. How many people really care about you?
12. If there is a cold or infection going around, how often do you usually catch it?
13. How often do you have to take medicine for any reason?
14. Do any problems with your balance affect the way you feel about yourself?
15. How much support do you have from your family?
16. How often are you inconvenienced by any problems with your balance?
17. How often do you participate in social activities?
18. How often do you feel inclined to withdraw from social situations?

GLOBAL INDEX OF SAFETY

The global index of safety (GIS) is an adverse event based instrument designed to evaluate the safety profile of drugs.

Abbreviated Name: GIS
Author(s): José Antonio Sacristán, Juan Carlos Gomez, Xavier Badia, Paul Kind
Purpose: To assess drug safety
Population: Adult
Type of Instrument: Utility
Mode of Administration:

Rater:	Self-administered
Time required:	5- 10 minutes
Response Options:	5-point Likert scale
Scoring:	Global score
Score Direction:	Lower scores show better QoL

Original Language: Spanish
Existing Translations : English

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Contact for information and permission to use:

José Antonio Sacristán
Lilly, S.A.
Avenida de la Industría, 30
28108 Madrid Spain
Tel: +34 91 663 5000
Fax: +34 91 663 5231
Email: Sacristan_Jose@lilly.com

Dimensions covered by the questionnaire :

- Urinary incontinence
- Urinary irritative/Obstructive symptoms
- Bowel/Rectal symptoms
- Sexuality
- Hormonal function/vitality

Key References:

1. Sacristan JA, Gomez JC, Badia X, Kind P. Global index of safety (GIS): a new instrument to assess drug safety. J Clin Epidemiol 2001; 54:1120-5

There is an asymmetry between the extraordinary development of measures and tools aimed at studying the beneficial effects of the drugs and the more limited methods to assess their safety profile. The goal of our study was to develop a global measuring tool to assess drugs' safety. We conducted a survey of Spanish psychiatrists in mental health centers and outpatient treatment units to assess the severity scores that they would assign to a list of the most common adverse events (AEs) that usually occur with antipsychotic treatment. The severity scores were then applied to the list of AEs that really occurred along a naturalistic pharmacoepidemiological study on the use of different antipsychotics in the treatment of schizophrenia. The Global Index of Safety (GIS) of the experimental group treated with olanzapine (OLZ) was compared with the GIS of the control group and with the GIS of specific antipsychotics for which the number of treated patients was greater than 100. A total of 194 psychiatrists rated the severity of each AE on a scale of 1 (insignificant) to 5 (extremely severe). The individual severity was applied to the 2949 schizophrenic patients included in a pharmacoepidemiological study. A GIS was calculated for every group of patients receiving the same treatments. The GIS of the control group was higher (4.3) than that calculated from the experimental group (2.5) ($P < 0.001$). The GIS of the risperidone (3.6) and haloperidol (6.0) subgroups were higher than that calculated from the OLZ group ($P < 0.001$). The development of a GIS may facilitate the comparison of the safety of several drugs and may constitute a very valuable aid for those involved in selecting drugs.

Item weights, standard deviations and fit statistics of the GIS items obtained through the psychiatrists participating in the EFESO and EUROPA studies

ID	Label	Weight (0–100)		Weight rank		Standard deviation		Outfit MNSQ	
		EFESO	*EUROPA*	*EFESO*	*EUROPA*	*EFESO*	*EUROPA*	*EFESO*	*EUROPA*
79	Thirst	0.00	0.00	1.0	1.0	0.71	0.67	0.97	0.83
41	Chills	0.72	3.97	2.0	2.0	0.74	0.72	0.91	1.05
89	Cough increased	1.57	5.09	3.0	4.5	0.69	0.60	0.74	0.66
80	Dry mouth	3.15	4.34	5.0	3.0	0.70	0.62	1.15	0.63
23	Sweating increased	3.15	5.09	5.0	4.5	0.70	0.72	0.97	0.84
83	Hot flushes	3.15	7.69	5.0	7.0	0.69	0.63	0.82	0.77
78	Rhinitis	4.43	8.19	7.0	10.0	0.73	0.68	0.82	0.54
42	Constipation	5.29	6.08	8.0	6.0	0.67	0.80	0.97	0.74
44	Pharyngitis	6.29	7.94	9.5	8.0	0.95	0.56	1.69	1.20
38	Dyspepsia	6.29	8.19	9.5	10.0	0.70	0.62	0.67	0.72
73	Weight loss	7.30	8.19	11.0	10.0	0.76	0.60	0.82	0.59
67	Nausea	8.58	9.80	12.0	13.0	0.69	0.67	0.64	0.59
24	Cephalea	9.87	12.90	13.0	15.0	0.73	0.62	0.68	0.62
85	Abnormal dreams	10.01	9.18	14.0	12.0	0.76	0.75	1.02	0.75
13	Anorexia	11.87	15.63	15.0	24.0	0.77	0.69	0.98	1.11
35	Dysmenorrhea	12.45	15.51	16.0	22.0	0.75	0.62	0.71	0.72
47	Gastritis	12.59	15.51	17.0	22.0	0.85	0.67	0.68	0.73
31	Back pain	12.73	15.76	18.0	25.0	0.71	0.63	0.92	0.94
65	Dizziness	13.73	15.51	19.5	22.0	0.69	0.69	0.67	0.61
71	Paraesthesia	13.73	16.13	19.5	27.0	0.79	0.63	0.77	0.88
91	Vasodilatation	14.45	14.27	21.0	19.0	0.82	0.65	0.88	0.68
19	Appetite increased	15.02	15.88	22.0	26.0	0.75	0.65	1.28	0.93
17	Asthenia	15.16	10.79	23.0	14.0	0.81	0.68	1.40	0.89
50	Increased salivation	15.31	13.65	24.0	16.0	0.67	0.74	0.74	0.55
68	Nervousness	16.02	14.27	25.0	19.0	0.71	0.80	0.79	0.76
32	Diarrhea	16.74	14.27	26.5	19.0	0.76	0.73	0.80	0.58
64	Malaise	16.74	17.62	26.5	29.0	0.76	0.77	1.00	1.23
12	Amenorrhea	17.60	19.35	28.0	30.0	0.75	0.79	1.20	0.94
84	Somnolence	17.88	13.90	29.0	17.0	0.69	0.88	1.08	0.74
70	Palpitation	18.60	21.71	30.0	34.5	0.79	0.75	0.83	1.10
36	Libido decreased	18.74	17.37	31.0	28.0	0.72	0.64	1.05	0.97
30	Abdominal pain	19.17	21.71	32.0	34.5	0.89	0.90	1.04	1.18
55	Hypotension	20.03	20.47	33.0	31.0	0.72	0.78	1.06	0.73
60	Urinary tract infection	21.60	25.19	34.0	46.0	0.72	0.76	1.34	0.83
14	Anxiety	21.75	21.46	35.0	33.0	0.95	0.90	0.92	0.82
29	Pain	21.89	20.72	36.0	32.0	0.91	0.63	0.95	1.16
86	Tachycardia	22.60	22.95	37.0	39.5	0.80	0.82	0.80	0.74
21	Weight gain	23.03	23.95	38.0	43.5	0.79	0.71	1.34	0.90
61	Insomnia	23.61	23.95	39.5	43.5	0.78	0.66	0.83	0.75
92	Vertigo	23.61	25.56	39.5	48.0	0.76	0.61	0.66	0.62
8	Orgasm dysfunction	24.18	23.95	41.0	43.5	0.74	0.76	0.99	0.87
6	Abnormal ejaculation	24.32	22.08	42.0	38.0	0.72	0.75	0.95	0.87
94	Vomiting	24.46	22.95	43.0	39.5	0.79	0.79	0.70	0.62
93	Blurred vision	25.75	21.96	44.0	37.0	0.77	0.63	0.93	0.67
4	Joint disorder	26.75	21.84	45.0	36.0	1.01	0.77	1.58	1.23
15	Apathy	26.90	23.20	46.5	41.0	0.79	0.76	1.31	0.90
87	Tremor	26.90	23.95	46.5	43.5	0.68	0.64	0.87	0.58
87	Tremor	26.90	23.95	46.5	43.5	0.68	0.64	0.87	0.58
88	Twitching	27.18	25.31	48.0	47.0	0.78	0.65	0.83	0.56
46	Galactorrhea	27.90	27.42	49.0	52.5	0.79	0.64	1.00	0.69
43	Euphoria	28.18	28.41	50.0	55.0	0.95	0.84	1.18	1.04
54	Hypotonia	29.18	26.05	51.0	49.0	0.76	0.66	0.80	0.62
10	Urinary frequency	30.19	28.04	52.0	54.0	0.77	0.69	0.84	0.56

Table continues

Table continued

ID	Label	Weight (0–100)		Weight rank		Standard deviation		Outfit MNSQ	
		EFESO	*EUROPA*	*EFESO*	*EUROPA*	*EFESO*	*EUROPA*	*EFESO*	*EUROPA*
74	Rash	30.90	26.80	53.0	50.0	0.89	0.67	1.15	1.11
22	Liver function test abnormal	31.19	29.40	54.0	57.0	0.84	0.62	1.08	0.85
40	Edema	31.62	30.27	55.0	60.0	0.97	0.85	1.16	1.00
58	Impotence	31.90	30.02	56.0	59.0	0.80	0.69	1.04	1.02
49	Prolactin increased	32.05	28.54	57.0	56.0	0.82	0.73	1.16	0.73
53	Hypokinesia	34.91	27.30	58.5	51.0	0.68	0.72	0.68	0.60
66	Myoclonia	34.91	31.14	58.5	61.5	0.87	0.84	1.16	0.84
49	Prolactin increased	32.05	28.54	57.0	56.0	0.82	0.73	1.16	0.73
53	Hypokinesia	34.91	27.30	58.5	51.0	0.68	0.72	0.68	0.60
66	Myoclonia	34.91	31.14	58.5	61.5	0.87	0.84	1.16	0.84
7	Speech disorder	35.62	27.42	60.0	52.5	0.72	0.78	0.71	0.89
1	Akathisia	35.91	29.78	61.0	58.0	0.77	0.72	1.16	0.81
20	Creatine phosphokinase increase	36.19	31.89	62.0	64.0	1.03	0.79	1.97	1.59
28	Depression	36.48	37.22	63.0	72.0	0.78	0.81	0.80	0.65
11	Amblyopia	36.62	31.14	64.0	61.5	0.94	0.98	1.20	0.92
48	Gynecomastia	37.77	31.39	65.0	63.0	0.87	0.76	1.04	1.04
56	Hostility	38.05	35.73	66.0	68.0	0.94	0.82	1.14	0.88
45	Fever	38.34	38.71	67.0	74.0	1.05	0.72	1.74	1.25
52	Hypertonia	38.77	34.12	68.0	67.0	0.75	0.76	0.76	0.74
5	Electrocardiogram abnormal	38.91	46.15	69.0	82.0	0.76	0.82	1.39	1.94
77	Rigidity	39.06	32.38	70.0	65.0	0.95	0.68	0.90	0.92
69	Oliguria	39.20	37.34	71.0	73.0	1.02	0.63	1.49	0.97
39	Dystonia	40.34	33.13	72.5	66.0	0.85	0.68	1.28	1.01
72	Extrapyramidal syndrome	40.34	36.72	72.5	70.0	0.71	0.78	1.00	0.52
9	Personality disorder	41.34	38.96	74.0	75.0	0.95	0.89	1.26	1.17
27	Oculogyric crisis	42.35	36.72	75.0	70.0	0.99	0.89	1.48	0.94
37	Dyspnea	43.35	48.14	76.0	84.0	0.94	0.69	1.24	0.92
51	Hypertension	44.06	43.92	77.0	79.0	0.87	0.73	0.89	0.60
18	Ataxia	44.78	36.72	78.0	70.0	0.78	0.85	0.82	0.66
59	Incoordination	45.92	39.33	79.0	76.0	0.79	0.64	0.71	0.65
33	Dyskynesia	46.07	41.07	80.0	77.0	0.79	0.78	0.91	0.76
81	Syncope	46.21	45.66	81.0	81.0	1.05	0.82	1.67	1.16
2	Agitation	48.07	43.18	82.0	78.0	0.86	0.91	1.18	1.14
90	Thinking abnormal	48.50	45.41	83.0	80.0	0.92	0.77	1.04	0.89
18	Ataxia	44.78	36.72	78.0	70.0	0.78	0.85	0.82	0.66
59	Incoordination	45.92	39.33	79.0	76.0	0.79	0.64	0.71	0.65
33	Dyskynesia	46.07	41.07	80.0	77.0	0.79	0.78	0.91	0.76
81	Syncope	46.21	45.66	81.0	81.0	1.05	0.82	1.67	1.16
2	Agitation	48.07	43.18	82.0	78.0	0.86	0.91	1.18	1.14
90	Thinking abnormal	48.50	45.41	83.0	80.0	0.92	0.77	1.04	0.89
76	Urinary retention	49.64	46.65	84.0	83.0	0.89	0.74	1.18	0.95
25	Confusion	52.07	50.25	85.0	86.0	0.88	0.80	0.96	0.71
16	Arrhythmia	54.51	56.95	86.0	88.0	0.89	0.71	1.39	1.26
57	Delirium	54.65	49.38	87.0	85.0	0.92	0.72	1.09	1.01
75	Paranoid reaction	56.37	52.98	88.0	87.0	0.86	0.74	0.89	0.75
34	Tardive dyskynesia	67.38	59.31	89.0	89.0	0.84	0.74	1.33	1.10
26	Convulsions	75.11	69.23	90.0	91.0	0.83	0.70	1.12	0.98
63	Leucopoenia	75.54	67.49	91.0	90.0	0.95	0.68	1.61	1.58
62	Suicide attempt	78.97	73.08	92.0	92.0	0.88	0.69	1.35	1.16
3	Agranulocytosis	88.27	86.10	93.0	93.0	0.88	0.53	3.45	1.52
82	Neuroleptic malignant syndrome	100.00	100.00	94.0	94.0	0.76	0.38	2.53	2.24

P.S. Sample of the GIS Instrument :
GIS is not the classical instrument that includes a list of questions, categories, etc.
The GIS instrument needs to be developed for every therapeutic area.

GLOBAL QUALITY OF LIFE SCALE

A global quality of life question which asks patients to provide an overall evaluation of QOL on a 100-point category rating scale.

Abbreviated Name: GQOL
Author(s): Michael Hyland & Samantha C. Sodergren
Purpose: To assess patients' overall perspective on quality of life
Population: Male
Age Range : 18 to 90 years
Type of Instrument: Quality of life
Mode of Administration: Self-administered

Rater:	Self-administered
Time required:	1 minute
Response Options:	A global scale
Scoring:	Global score: Minimum score: 0 / Maximum score: 100
Score Direction:	Higher scores show better QoL

Number of Items: 1
Original Language: English

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Contact for information and permission to use:

Professor Michael E. Hyland
Department of Psychology
University of Plymouth
Drake Circus
Plymouth, Devon, PL4 8AA UK
Phone: +44 1752 233157 (secretary) / 233144 (direct)
Fax: +44 1752 233176
Email: mhyland@plymouth.ac.uk

Dimensions covered by the questionnaire :

- Uni-dimensional assessing overall quality of life

Key References:

1. Hyland, M. E. & Sodergren, S. C. Which global quality of life scale is most reliable and most preferred? Quality of Life Research 1997: 6 (Abstracts: 4th Annual Conference of ISOQOL, 167); 662-63.

Global quality of life (QoL) scales provide one kind of subjective judgement which patients can make about their health. We examined the reliability and preference of 12 scales: four category scales with end labels, four visual analogue scales and four specially designed H scales based on the principles originally developed by Borg for symptom assessment. Eighty undergraduates and 15 residents of a residential home for the elderly completed self-assessment using all 12 scales as well as completing preference ratings. As a measure of reliability, we examined the intercorrelations in a self-rating between the different types of scale. The H scales were most reliable and the visual analogues least reliable but the mean difference between the scales was less than 10% and in the majority of cases less than 5%. For both the undergraduates and the elderly the easiest to use were the H scales and these were felt to give the most accurate representation of QoL. Only six elderly people expressed a preference but both they and the undergraduates preferred one of the H scales. Visual analogue scales were perceived to be the most difficult to use and least preferred of choices overall.We conclude that, although the differences in score between different global QoL scales is small, user preference suggests the use of the H scale over standard category rating scales and category rating scales over visual analogue scales.

Global Quality of Life Scale

100	Perfect quality of life
95	Nearly perfect quality of life
90	
85	Very good quality of life
80	
75	
70	Good quality of life
65	
60	Moderately good quality of life
55	
50	
45	
40	Somewhat bad quality of life
35	
30	Bad quality of life
25	
20	
15	Very bad quality of life
10	
5	Extremely bad quality of life
0	No quality of life

Write any number between 0 and 100 that describes your quality of life: _____

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GRONINGEN ACTIVITY RESTRICTION SCALE

The Groningen Activity Restriction Scale (GARS) is a non-disease-specific instrument to measure disability in activities of daily living and instrumental activities of daily living. It was developed in studies of Dutch samples consisting of elderly or chronically ill people.

Abbreviated Name: GARS
Author(s): G.I.J.M. Kempen
Purpose: To measure both the ADL and instrumental ADL disability in community-based studies with respect to the aid and services provided by professional home help and district nursing agencies
Population: Adult
Age Range : 18+ years
Type of Instrument: Disability / Physical functioning
Mode of Administration:

Rater:	Self-/ Interviewer-administered
Time required:	10 minutes
Response Options:	4-point Likert scale
Scoring:	Global score: Minimum score: 18 / Maximum score: 72
Score Direction:	Lower scores show better QoL

Number of Items: 18
Original Language: Dutch
Existing Translations : French, Norwegian, Swedish
For information on, or permission to use:

Contact for information and permission to use:

G.I.J.M. Kempen, PhD
Professor of Social Gerontology
Faculty of Health Sciences
Maastricht University
P.O. Box 616, 6200 MD Maastricht
The Netherlands
Fax: +31 43 3884169
E-mail: G.Kempen@zw.unimaas.nl

Dimensions covered by the questionnaire :

- Activities of the daily living
- Instrumental activities of the daily living

Key References:

1. Kempen GI, Miedema I, Ormel J, Molenaar W. The assessment of disability with the Groningen Activity Restriction Scale. Conceptual framework and psychometric properties. Soc Sci Med 1996; 43:1601-10

The conceptual framework, psychometric properties, descriptive statistics, and the rules for administration and scoring of the Groningen Activity Restriction Scale (GARS) for assessing disability in the area of ADL (Activities of Daily Living including mobility) as well as IADL (Instrumental Activities of Daily Living) are presented. The result show that the GARS, which can be administered both face-to-face and by mail questionnaire, is an easy to administer, comprehensive, reliable, hierarchical, and valid measure for assessing disability in older people. By integrating previously developed scales measuring different domains of disability (ADL, IADL, and mobility) and the use of a four-category response format, an accurate and detailed measure of disability can be obtained and a broader range of needs of subjects can be described. The GARS manual, including detailed procedures for administration and scoring, encourages unambiguous administration and interpretation which results in more comparable research outcomes.

GARS-4[1]

Inleiding:
De volgende vragen gaan erover of u *op dit moment* een aantal werkzaamheden, die regelmatig gedaan moeten worden, zelfstandig kunt uitvoeren. Als u bepaalde werkzaamheden wel zelf kunt doen, kunt u daarbij ook aangeven of u deze werkzaamheden met of zonder moeite kunt doen:

- kunt u bepaalde werkzaamheden zonder moeite volledig zelf dan omcirkelt u een 1;
- indien u ze wel zelfstandig kunt doen maar daar wel enige moeite mee heeft dan omcirkelt u een 2;
- indien u ze wel zelfstandig kunt doen maar daar wel veel moeite mee heeft dan omcirkelt u een 3;
- indien u bepaalde werkzaamheden niet zelfstandig kunt maar alleen met hulp van anderen dan omcirkelt u een 4.

Bijvoorbeeld:

Kunt u, geheel zelfstandig, uw maaltijden verzorgen?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
	(2)	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
	3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
	4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen

Als u de activiteit genoemd in dit voorbeeld wel geheel zelfstandig maar alleen met enige moeite kunt, dan omcirkelt u een 2.
Nogmaals, het gaat er dus niet om of u bepaalde werkzaamheden ook werkelijk doet, maar of u ze zou kunnen verrichten (indien dat nodig is of nodig mocht zijn).

Zie volgende bladzijde

[1] © Kempen, 1993, Noordelijk Centrum voor Gezondheidsvraagstukken, Rijksuniversiteit Groningen.

Dan volgen nu de vragen:

1	Kunt u zich, geheel zelfstandig aan- en uitkleden?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
2	Kunt u, geheel zelfstandig, in en uit bed komen?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
3	Kunt u, geheel zelfstandig, vanuit een stoel overeind komen?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
4	Kunt u, geheel zelfstandig, uw gezicht en handen wassen?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
5	Kunt u, geheel zelfstandig, uw hele lichaam wassen en afdrogen?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
6	Kunt u, geheel zelfstandig, van en naar het toilet gaan?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
7	Kunt u, geheel zelfstandig, eten en drinken	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
8	Kunt u, geheel zelfstandig, rond-lopen in huis (eventueel met stok)?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
9	Kunt u, geheel zelfstandig, de trap op en aflopen?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen

10	Kunt u, geheel zelfstandig, buitenshuis rondlopen (eventueel met stok)?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
11	Kunt u, geheel zelfstandig, uw voeten en teennagels verzorgen?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
12	Kunt u, geheel zelfstandig, ontbijt of lunch klaarmaken?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
13	Kunt u, geheel zelfstandig, warm eten klaarmaken?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
14	Kunt u, geheel zelfstandig, "lichte" huishoudelijke werkzaamheden verrichten (bijv. stof afnemen of prullen opruimen)?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
15	Kunt u, geheel zelfstandig, "zware" huishoudelijke werkzaamheden verrichten (bijv. dweilen, ramen lappen of stofzuigen)?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
16	Kunt u, geheel zelfstandig, uw kleren wassen en strijken?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
17	Kunt u, geheel zelfstandig, de bedden verschonen en / of opmaken?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen
18	Kunt u, geheel zelfstandig, de boodschappen doen?	1	**Ja,** dat kan ik geheel zelfstandig zonder enige moeite
		2	**Ja,** dat kan ik geheel zelfstandig, maar wel met enige moeite
		3	**Ja,** dat kan ik geheel zelfstandig, maar met veel moeite
		4	**Nee,** dat kan ik niet zelfstandig, maar alleen met hulp van anderen

Groningen Activity Restriction Scale—GARS

The following questions refer to daily activities which should be performed frequently. In each question it is asked whether you *are able to perform* the activity at this moment. It is not intended to assess whether you are actually performing the activities, but if you can do them if necessary.

Response categories for each item

1. Yes, I can do it fully independently without any difficulty
2. Yes, I can do it fully independently but with some difficulty
3. Yes, I can do it fully independently but with great difficulty
4. No, I cannot do it fully independently, I can only do it with someone's help

GARS items

1. Can you, fully independently, dress yourself?
2. Can you, fully independently, get in and out of bed?
3. Can you, fully independently, stand up from sitting in a chair?
4. Can you, fully independently, wash your face and hands?
5. Can you, fully independently, wash and dry your whole body?
6. Can you, fully independently, get on and off the toilet?
7. Can you, fully independently, feed yourself?
8. Can you, fully independently, get around in the house (if necessary with a cane)?
9. Can you, fully independently, go up and down the stairs?
10. Can you, fully independently, walk outdoors (if necessary with a cane)?
11. Can you, fully independently, take care of your feet and toenails?
12. Can you, fully independently, prepare breakfast or lunch?
13. Can you, fully independently, prepare dinner?
14. Can you, fully independently, do "light" household activities (for example, dusting and tidying up)?
15. Can you, fully independently, do "heavy" household activities (for example mopping, cleaning the windows and vacuuming)?
16. Can you, fully independently, wash and iron your clothes?
17. Can you, fully independently, make the beds?
18. Can you, fully independently, do the shopping?

HEALTH ACTIVITIES AND LIMITATIONS INDEX

The HALex was developed by the National Center for Health Statistics as a composite health status measure that can be calculated by using the responses to the National Health Interview Survey.

Abbreviated Name: HALex
Author(s): Pennifer Erickson
Purpose: To offer a method of utility assessment using existing values from the National Health Interview Survey (NHIS) and a utility algorithm to derive preferences
Population: Adult
Age Range : 18+ years
Type of Instrument: Quality of Life/ Utility
Mode of Administration:

Rater:	Self-/ Telephone-administered
Time required:	15-20 minutes
Response Options:	Yes/No and 5-point Likert scale
Scoring:	Global score: Minimum score: 0.0 / Maximum score: 1.0
Score Direction:	Higher scores show better QoL
Weighting:	Yes

Number of Items: 14
Original Language: English

Copyright: Pennifer Erickson

Contact for information and permission to use:

Pennifer Erickson, PhD.
Pennsylvania State University
Health and Human Development East
PA USA
Phone: +1 814-863-7256
Fax: +1 814-863-7525
E-mail: pae6@psu.edu

Dimensions covered by the questionnaire :

- Perceived Health
- Activity Limitation

Key References:

1. Erickson P. Evaluation of a population-based measure of quality of life: the Health and Activity Limitation Index (HALex). Qual Life Res 1998; 7:101-14

This paper briefly discusses the rationale and methods for developing and evaluating the Health and Activity Limitation Index (HALex), a generic measure of health that consists of two attributes: perceived health and activity limitation. Using a multiattribute utility scoring system, information from these attributes was combined to form a single score that represents health-related quality of life (QoL) on a 0.0-1.0 continuum. The construct and incremental validity are evaluated using data from a sample of over 40,000 adults who participated in the 1990 US National Health Interview Survey. The health state distributions for known groups, defined in terms of personal or lifestyle characteristics such as sex, age and smoking status, were comparable to those for similarly defined states that have been studied by other researchers. Of the regression models examined in this analysis, age, years of schooling and being in a high-risk group based on body mass index (BMI) were found to have the largest impact on health as measured by the HALex. Although this measure was developed to be combined with mortality data to form a quality-adjusted life year (QALY) for detecting changes in the health of the US population from 1990 to 2000, it may also be useful for inclusion in clinical studies, in particular as the national data are readily available for use as norms.

2. Bradley CJ, Kroll J, Holmes-Rovner M. The health and activities limitation index in patients with acute myocardial infarction. J Clin Epidemiol 2000;53:555-62

Utility assessment is required to estimate quality-adjusted life years, but is often avoided due to the cumbersome nature of elicitation techniques. The Health Activities and Limitations Index (HALex) offers a method of utility assessment using existing values from the National Health Interview Survey (NHIS) and a utility algorithm to derive preferences. The authors assessed the construct validity of the HALex by comparing derived values with directly assessed HALex utilities in patients post acute myocardial infarction (AMI). OLS regression was used to model the relationship between utilities and patient demographics, comorbidities, and treatment. The mean and median utility for patients (n = 160) was.57 (SD = 22) and.55 respectively, and was not statistically different from the mean [.57 (SD =.30)] and median (.58) for similar NHIS respondents (n = 46). Patients with a comorbidity index of three or less had mean utilities.13 higher than the mean utility for patients with an index of four or more. No relationship was found between patients' age, race, and income and their utilities. The HALex scoring algorithm is a promising means to obtain utilities, and provides a methodology to easily estimate utilities for patients, but is not without limitations.

HALex questionnaire

Based on the Behavioral Risk Factor Surveillance Survey: CDC Telephone Administered Version.

1. Would you say that in general your health is:
   - a. Excellent 1
   - b. Very good 2
   - c. Good 3
   - d. Fair 4
   - e. Poor 5

   Do not read the following responses.
   - Do not know/not sure 7
   - Refused 9

Section A: ages 18–69 years of age

1. What were you doing most of the past 12 months?
   - a. Working at a job or business 1
   - b. Keeping house Go to Q. 4 2
   - c. Going to school Go to Q. 6 3
   - d. Something else Go to Q. 6 4

   - Do not know/not sure 7
   - Refused 9

2. Does any impairment or health problem now keep you from working at a job or business?
   - a. Yes Go to Q. 9 1
   - b. No 2

   - Do not know/not sure 7
   - Refused 9

3. Are you limited in the kind or amount of work you can do because of any impairment or health problem?
   - a. Yes Go to Q. 9 1
   - b. No Go to Q. 8 2

   - Do not know/not sure 7
   - Refused 9

4. Does any impairment or health problem now keep you from doing any housework at all?
   - a. Yes Go to Q. 6 1
   - b. No 2

   - Do not know/not sure 7
   - Refused 9

5. Are you limited in the kind or amount of housework you can do because of any impairment or health problem?
   a. Yes 1
   b. No 2

   Do not know/not sure 7
   Refused 9

6. Does any impairment or health problem keep you from working at a job or business?
   a. Yes Go to Q. 9 1
   b. No 2

   Do not know/not sure 7
   Refused 9

7. Are you limited in the kind or amount of work you could do because of any impairment or health problem?
   a. Yes Go to Q. 9 1
   b. No 2

   Do not know/not sure 7
   Refused 9

If Yes to Q. 4 or Yes to Q. 5, go to Q. 9.

8. Are you limited in any way in any activities because of any impairment or health problem?
   a. Yes 1
   b. No Go to closing statement 2

   Do not know/not sure 7
   Refused 9

9. Because of any impairment or health problem, do you need the help of other persons with your personal care needs, such as eating, bathing, dressing or getting around the house?
   a. Yes 1
   b. No 2

   Do not know/not sure 7
   Refused 9

10. Because of any impairment or health problem, do you need the help of other persons in handling your routine needs, such as everyday household chores, doing necessary business, shopping or getting around for other purposes?
   a. Yes Go to closing statement 1
   b. No Go to closing statement 2

   Do not know/not sure Go to closing statement 7
   Refused Go to closing statement 9

Section B: ages 70 and older

11. **Because of any impairment or health problem, do you need the help of other persons with your personal care needs, such as eating, bathing, dressing or getting around the house?**
    a. Yes 1
    b. No 2

    Do not know/not sure 7
    Refused 9

12. **Because of any impairment or health problem, do you need the help of other persons in handling your routine needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?**
    a. Yes Go to closing statement 1
    b. No 2

    Do not know/not sure 7
    Refused 9

13. **Are you limited in any way in any activities because of any impairment or health problem?**
    a. Yes 1
    b. No 2

    Do not know/not sure 7
    Refused 9

HEALTH AND DAILY LIVING FORM

The Health and Daily Living Form (HDLF) is a structured assessment for patient and community groups that assesses health related factors such as alcohol consumption, drinking problems, and depression. It is a structured assessment procedure that can be administered either as an interview or as a questionnaire, and can be used with both patient and community groups.

The HDLF includes items covering socio-demographic factors as well as sets of indices that tap health-related and social functioning, chronic and acute life stressors, social resources, and help-seeking responses. While some of the indices are adapted from the work of other investigators, newer indices have been developed that may prove useful to investigators interested in the process of psychosocial adaptation among psychiatric and medical populations and among community populations.

Abbreviated Name: HDLF
Author(s): Rudolf H. Moos, Ruth C. Cronkite, John W. Finney
Purpose: To focus on the social resources people use to prevent and adapt to stressful life circumstances
Population: Adult (Adult Form) & Adolescent (Youth Form)
Age Range : 12 and over
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-administered
Time required:	40 minutes
Response Options:	Yes/No and Likert scale
Scoring:	Scores by dimension
Score Direction:	Lower scores show better QoL

Number of Items: Adult Form: 105 items / Youth Form: 14 items
Original Language: English

Copyright: 1984, 1990, Rudolf H. Moos, Center for Health Care Evaluation, Stanford University Medical Center, Palo Alto, CA 94305.

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Mind Garden, Inc
1690 Woodside Road, Suite 202
Redwood City, CA 94061, USA
Phone: 650-261-3500
Fax: 650-261-3505
Email: info@mindgarden.com

Dimensions covered by the questionnaire :

The HDLF includes items covering socio-demographic factors as well as sets of indices that tap health-related and social functioning, chronic and acute life stressors, social resources, and help-seeking responses.

- Individual functioning
- Stressful Life Circumstances
- Social Network Resources
- Help-Seeking Responses

Key References:

1. Billings AG, Moos RH. The role of coping responses and social resources in attenuating the stress of life events. Journal of Behavioural Medicine. 1981; 2: 139-157.

The nature of individual coping responses to stressful life events was explored in a representative adult community sample. Two approaches to the classification of coping strategies were operationalized. Using these measures, small but significant gender and contextual differences in coping were identified. Mood and symptom levels were related to coping responses and to quantitative and qualitative measures of social resources. Measures of coping and social resources attenuated the relationship between undesirable life events and personal functioning.

SAMPLE PAGES

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Health and Daily Living – Adult Form B

This is your copy of the Health and Daily Living Form. Please answer each question as accurately as you can by placing an "X" in the box next to the answer that you select or by entering information in the space provided.

All your anwers are strictly confidential. If you do not wish to answer a question, please circle the question so that we know you have decided to skip it.

Please ignore the small numbers by the boxes and in the margins. They help us record your answers. We appreciate your cooperation in this important survey.

PART I. Some Facts about You

1. Gender 1 O Male 2 O Female

2- When were you born ? _____ _____ _____
month day year

3-How many years of school did you finish ? (Circle last year COMPLETED)

HİGH SCHOOL					COLLEGE/VOCATIONAL SCHOOL				
8 or less	9th	10th	11th	12 th	1st	2nd	3rd	4th	5or more
08	09	10	11	12	13	14	15	16	17

4-What is your religious preference ?

1 O Catholic 2 O Jewish 3 O Protestant 4 O Other 5 O None

PART I. Some Facts about You (continued)

5- What is your ethnic background ?

1 o Native American 2 o Asian 3 o Black 4 o Hispanic Latino 5 o Caucasian 6 o Other

6- What is your present marital status ?

1 o o	2 o o	3 o o	4 o o	5 o o
Never Married	Married	Separated	Divorced	Widowed
	How long have you been married tour present spouse? _____years	How long did you live with your spouse before you separated? _____years	How long were you married your (last) spouse? _____years	

PART II. Employment History and Current Status

1- DURING THE LAST YEAR , how many times did you change jobs ? _____ times

2- Are you employed now ?

1 No 2 Yes, part time only 3 Yes, full time only 4 Yes, full time and part time

3- What is your present (or usual if not currently employed) occupation ?

Be as specific as you can.

PART III. Your Health In the Last 12 Months

1 . Here is a list of medical conditions that usually last some time.
DURING THE LAST 12 MONTHS, have you had any of these conditions ?
(Mark "Yes" only if diagnosed by a physician.)

Yes 1	No 2		Yes 1	No 2	
O O	O O	Anemia (low blood)	O O	O O	Serious back trouble
O O	O O	Asthma	O O	O O	Heart trouble
O O	O O	Arthritis or rheumatism	O O	O O	High blood pressure
O O	O O	Bronchitis	O O	O O	Kidney trouble
O O	O O	Cancer	O O	O O	Stroke
O O	O O	Chronic liver trouble	O O	O O	Tuberculosis
O O	O O	Diabetes	O O	O O	Ulcer

2. Here is a list of physical symptoms. Have you experienced any of them FAIRLY OFTEN IN THE PAST 12 MONTHS ?

Yes 1	No 2		Yes 1	No 2	
O O	O O	Felt weak all over	O O	O O	Acid stomach or indigestion
O O	O O	Suddenly felt hot all over	O O	O O	Cold Sweats
O O	O O	Heart beating hard, pounding	O O	O O	Hands trembling
O O	O O	Poor appetite	O O	O O	Headaches
O O	O O	Nervousness (fidgety, tense)	O O	O O	Constipation
O O	O O	Restlessness, couldn't sit stil	O O	O O	Insomnia (trouble falling asleep or staying asleep)

PART IV. Your Health in the Last Month

We have asked you about your general health over the last year. Now we would like to know how you have been feeling DURING THE LAST MONTH.
DURING THE LAST MONTH , how often have you experienced the following ?

	Never	Seldom	Some-times	Fairly often	Often
	1	2	3	4	5
1- Feeling depressed (sad or blue)	O O	O O	O O	O O	O O
2-Poor appetite or weight loss	O O	O O	O O	O O	O O
3-Trouble sleeping or sleeping too much	O O	O O	O O	O O	O O
4-Loss of energy; fatigue, tiredness	O O	O O	O O	O O	O O
5-Been unable to sit stil	O O	O O	O O	O O	O O
6-Feeling slowed down and having trouble moving	O O	O O	O O	O O	O O
7-Loss of interest or pleasure in your usual activities or sex	O O	O O	O O	O O	O O
8-Feeling guilty, worthless, or down on yourself	O O	O O	O O	O O	O O
9-Troubled concentrating, thinking or making decisions	O O	O O	O O	O O	O O
10-Thoughts about death or suicide	O O	O O	O O	O O	O O
11-Crying	O O	O O	O O	O O	O O
12-Feeling negative or pessimistic	O O	O O	O O	O O	O O
13-Brooding about unpleasant things	O O	O O	O O	O O	O O
14-Feeling inadequate	O O	O O	O O	O O	O O
15-Feeling resentful, irritable, angry	O O	O O	O O	O O	O O

16-Needing reassurance or help	O O	O O	O O	O O	O O
17-Feeling sorry for yourself	O O	O O	O O	O O	O O
18-Physical symptoms or complaints	O O	O O	O O	O O	O O

HEALTH AND LABOUR QUESTIONNAIRE

Health and Labour Questionnaire (HLQ) develop for collecting quantitative data about the relation between illness, treatment and work-performance. Absence from work, reduced productivity at paid work, unpaid labour production and impediments to paid and unpaid labour are four dimensions that are address in the Health and Labour Questionnaire.

Abbreviated Name: HLQ
Author(s): Leona Hakkaart-van Roijen, Marie-Louise Essink-Bot & Marc A. Koopmanschap.
Purpose: To collect quantative data on the relationship between illness and treatment and work performance
Population: Adult
Age Range : 12 years and older
Type of Instrument: Work
Mode of Administration:

Rater:	Self-administered
Time required:	10 minutes
Response Options:	Likert scale
Scoring:	Scores by dimension
Score Direction:	Lower scores show better QoL

Number of Items: 17
Original Language: Dutch
Existing Translations : English, French, German, Spanish, Swedish

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Contact for information and permission to use:

Leona Hakkaart-van Roijen
Institute for Medical Technology Assessment
Erasmus University Rotterdam
P.O. Box 1738 3000 DR Rotterdam
Phone: +31 10 4088567
Fax: +31 10 4089094
Email: l.hakkaart-vanroijen@erasmusmc.nl

Dimensions covered by the questionnaire :

- Absence from work (3 items)
- Reduced productivity at paid work (9 items)
- Unpaid labour production (3 items)
- Impediments to paid and unpaid labour (2 items)

Key References:

1. van Roijen L, Essink-Bot ML, Koopmanschap MA, Bonsel G, Rutten FF. Labor and health status in economic evaluation of health care. The Health and Labor Questionnaire. Int J Technol Assess Health Care. 1996 Summer;12(3):405-15.

A health care program may influence both costs and health effects. We developed the Health and Labor Questionnaire (HLQ), which consists of four modules, to collect data on absence from work, reduced productivity, unpaid labor production, and labor-related problems. We applied the HLQ in several studies, and the results are encouraging.

Questionnaire on Health and Labour

(UK English Version)

July 2002

QUESTIONNAIRE ON HEALTH AND LABOUR

This questionnaire asks about the effects of health problems on paid and unpaid work (e.g domestic tasks). The term 'health problems' refers to acute or chronic physical illnesses, symptoms or disabilities. Other health problems like chronic fatigue or pain are also covered by this. Furthermore, psychological disorders are also included.
At the end of the questionnaire you will be asked for your age and some other personal details. These details will assist us in gaining a more clear understanding of your answers. There are no 'correct' or 'incorrect' answers to the questions asked. We are interested only in your personal opinion.

Before filling in the form kindly write down the date

Day……month…….year……

In addition to the questions relating to paid work there are some concerning unpaid work such as domestic duties. Throughout this questionnaire please limit your answers to your personal situation during the PAST TWO WEEKS.

1. Do you have paid employment?

☐ Yes, I work……hours per WEEK, divided over……DAYS; my occupation is…….., position……..

Go to the section Paid Work

☐ No
Please continue with question 14 (page 4)

*If your answer to the above question was **yes**, please continue by answering questions 2 to 13 (even if you are suffering from a short term illness at the present moment).*
*If your answer to the above question was **no**, please ignore questions 2 to 13 and continue with question 14.*

PAID WORK

We would like you to indicate on which working days in the **past two weeks** you were unable to perform paid work due to health problems. You are requested to complete question 2 using the following codes. In filling in the table for question 2 you may use more than one letter.

'W' = performed paid work
'U' = unable to perform paid work due to health problems
'O' = no paid work performed due to other reasons (weekend, public holidays, holidays etc.)

If you have part-time employment then fill in 'O' for the days on which you were not required to work. When you worked for half a day please indicate this e.g. by writing 'W/O' if you did not work in that afternoon.
In the case of illness during the weekend fill in 'O' if you were not required to work and 'U' if you were required to work.

Example:

Imagine you have four days paid employment per week, but last week you were unable to work on Thursday and Friday due to health problems. You always have Wednesdays off. Then the table would appear as follows:

MO	TU	WE	TH	FR	SA	SU	MO	TU	WE	TH	FR	SA	SU
W	W	O	W	W	O	O	W	W	O	U	U	O	O

The week before last ***Last week***

This was an **example**

2. Please complete the table below in the same manner. Remember that the time period concerned is the past two full weeks, counting back from last weekend.

'W' = performed paid work
'U' = unable to perform paid work due to health problems
'O' = no paid work performed due to other reasons (weekend, public holidays, holidays etc.)

MO	TU	WE	TH	FR	SA	SU	MO	TU	WE	TH	FR	SA	SU

The week before last ***Last week***

Only answer the following question if you have been completely unable to perform paid work due to health problems during the past two weeks.

3. When did this period of illness start? Enter the date on which you reported sick.
Day……month……year……

Health problems sometimes force people to be absent from their work. It is also possible that people go to work but are unable to perform their duties with the same efficiency as usual due to health problems. Questions 4 to 13 relate to this subject.

4. Were you hindered by health problems at your paid work over the past two weeks?

☐ No, not at all ➔ Go to question 13 (page 4)

☐ Yes, to a degree

☐ Yes, very much

Below you will find a number of statements that could be applicable to people with health problems in relation to their current work situation. Please indicate for each statement that is mentioned how often it applied to you in the past two weeks.

I **did** go to work but as a result of health problems…….

	(almost) never	sometimes	often	(almost) always
5. ..I had a problem concentrating	☐	☐	☐	☐
6. ..I had to go to work at a slower pace	☐	☐	☐	☐
7. ..I had to seclude myself	☐	☐	☐	☐
8. ..I found decision-making more difficult	☐	☐	☐	☐
9. ..I had to put off some of my work	☐	☐	☐	☐
10. ..Others had to take over some of my work	☐	☐	☐	☐

11. ..I had other problems, namely (please specify)…….....……

12. How many **extra** hours would you have to work to catch up on tasks you were unable to complete in normal working hours due to health problems over the past two weeks?
NOTE: Do **not** count the days on which you reported sick
……Hours

13. We would now like to know what your **net** earnings (after tax) are from your paid work. NOTE: this concerns your income, not including that of your partner (if any). You only need to fill out **one** of the following options.

☐ My own net income (after tax) from paid work is approximately:

	STUDY STAFF ONLY
£……per WEEK	€……
£……per 4 WEEKS	€……
£……per MONTH	€……
£……per YEAR	€……

☐ I do not know what my net income is or I would rather not say

Now go to question 15.
Question 14 should only be answered by people who do not/ no longer have paid work at the present time.

14. You have no paid work. Which of the following situations is most applicable to you?

☐ I have the daily task of running a household (which may include looking after children)

☐ I receive a pension or have taken early retirement

☐ I am still at school or a student

☐ I am unable to perform paid work due to health problems (If you did have paid work before would you fill out your occupation and the position you held: Occupation……, Position……)

☐ I have no paid work for other reasons (for example involuntary unemployment, voluntary work, etc.)

TO BE COMPLETED BY ALL RESPONDENTS

The following questions concern unpaid work. Here a distinction has been made between work in the household; shopping; odd jobs and duties; and activities for or with the children. We would like ***everyone*** *to please answer these questions. Firstly you will be asked how many hours a week you spent on each activity. If you did not perform a particular activity then simply write "0" hours.*

Secondly we would like to know whether you were hindered in any of the activities mentioned by health problems.
Please remember that your answers should relate to the PAST TWO WEEKS.

15. How many hours a week did you spend on:

- Work in the household (e.g. preparing meals, cleaning the house, washing clothes) ..…hours **per week**
- Shopping (e.g. shopping for the daily groceries, other types of shopping, going to the bank or post office) ..…hours **per week**
- Odd jobs and duties (e.g. house repairs, gardening, fixing the car, a bicycle or moped etc) ……..…hours **per week**
- Doing things for or with children living with you (e.g. caring for them, playing with them, taking them to school, helping with homework) ……..…hours **per week**

16. It may be that people with health problems who normally do household tasks (cleaning the house, shopping, taking care of the children) must leave these tasks to be done by others due to their health problems.

Have others taken over any of your household tasks due to your health problems?
(You may tick more than one box if applicable).

☐ Yes, family members (e.g. partner, children) have taken over my household tasks for ...……..hours **per week**

☐ Yes, others (e.g. wider or remaining family, neighbours or volunteers) have taken over my household tasks for ....……..hours **per week**

☐ Yes, I have had a home-help for ……..…..hours **per week**

☐ Yes, I have had another type of paid help (e.g. cleaner, handyman) for ……..…..hours **per week**

☐ No, I have performed my household tasks myself.

In the next table we would like you to indicate which of the following unpaid activities you have performed in the PAST TWO WEEKS and whether or not you were hindered by health problems. Please tick the appropriate answer.

First we will give two examples:

Example 1

During the PAST TWO WEEKS Mrs. Johnson did no go shopping in the city due to her health problems. She did manage to go to her local corner shop in spite of her problems. She indicates this as follows:

	DID DO		DID NOT DO	
	Was hindered by health problems	Was not hindered by health problems	Due to health problems	Other reason
Shopping	X			

Example 2

Mr. Cook never vacuums. His son always performs this task because Mr. Cook hates doing it. Mr. Cook answered the question on vacuuming as follows:

	DID DO		DID NOT DO	
	Was hindered by health problems	Was not hindered by health problems	Due to health problems	Other reason
Vacuuming				X

These were two **examples.**

17. Would you now complete the table below in the same way as shown in the two examples. Put a tick next to any activity that you did or did not perform in the PAST TWO WEEKS. If your answer is "DID DO" then indicate whether or not you were hindered by health problems. If your answer is "DID NOT DO" then please indicate whether or not this was due to health problems.

	DID DO		**DID NOT DO**	
	Was hindered by health problems	Was not hindered by health problems	Due to health problems	Other reason
Household work at home (for example, preparing meals, cleaning, washing clothes)				
Shopping (for example, daily groceries, other shopping, going to the bank or post office)				
Odd jobs and duties (for example, house repairs, gardening, fixing the car, a bicycle or moped etc)				
Doing things for or with children living with you (for example, caring for them, playing with them, taking them to school, helping with homework)				

The following questions concern a general nature

1. Are you:

   ☐ Male

   ☐ Female

2. What is your date of birth? Day……month……..year……

3. Which of the following levels of education have you completed? (You may tick more than one answer if applicable)

   ☐ None

   ☐ Primary school

   ☐ O Levels / CSEs / GCSEs / School Certificate

   ☐ Foundation NVQ / NVQ Levels 1-3 / Intermediate and Advanced GNVQ

   ☐ NVQ Levels 4-5 / HNC / HND

   ☐ Other Qualifications (e.g. City and Guilds, RSA/OCR, BTEC/Edexcel)

   ☐ AS Levels

   ☐ A Levels / Higher School Certificate

   ☐ First Degree (e.g. BA, Bsc)

   ☐ Higher Degree (e.g. MA, PhD, PGCE, post-graduate certificate/diplomas)

4. How many people live in your household?

   ☐ I live alone

   ☐ I live with one or more people

5. Are there any children in your household?

   ☐ Yes ➔ the age of the youngest child in the household is……..years

   ☐ No

6. Below is a list of chronic conditions and illnesses. Would you please indicate whether you are suffering from or have suffered from any of these conditions in the LAST TWELVE MONTHS?

	Suffering from now or have suffered from in the LAST TWELVE MONTHS:	
	YES	NO
Asthma or chronic bronchitis	☐	☐
Serious heart condition or heart infarct	☐	☐
High blood pressure	☐	☐
A stroke or its consequences	☐	☐
Stomach or duodenal ulcer	☐	☐
Serious intestinal disorders, lasting longer than three months	☐	☐
Gall stones or infection of the gall bladder	☐	☐
Liver condition or cirrhosis of the liver	☐	☐
Kidney stones	☐	☐
Serious kidney condition	☐	☐
Complaint of the prostate gland	☐	☐
Diabetes	☐	☐
Thyroid gland condition	☐	☐
Back problems of a persistent nature, slipped disc or sciatica (sharp pain usually starting from the back and extending to the buttock and/or leg)	☐	☐
Arthritis of the knees, hips or hands	☐	☐
Rheumatism of the hands and/ or feet	☐	☐
Other rheumatic conditions	☐	☐
Epilepsy	☐	☐
Other nervous disorders such as Parkinson's disease, multiple sclerosis	☐	☐
Serious headaches	☐	☐
Migraine	☐	☐
Malignant condition or cancer	☐	☐

	YES	NO
Overexertion, depression, serious nervousness	☐	☐
Chronic skin condition or eczema	☐	☐
Prolapse (the forward or downward movement of a part or organ e.g. bladder, uterus, rectum)	☐	☐
Varicose veins	☐	☐
Injury due to an accident in or around the house, a road traffic accident, sports injury at school or at work	☐	☐

This is the end of the questionnaire. Thank you very much for your co-operation. The space below has been provided for any comments you may wish to make about this questionnaire

……

……

……

……

……

……

HEALTH ASSESSMENT QUESTIONNAIRE

The Health Assessment Questionnaire (HAQ) was originally developed in 1978 by James F. Fries, and colleagues at Stanford University. It was one of the first self-report functional status (disability) measures and has become the dominant instrument in many disease areas, including arthritis. It is widely used throughout the world and has become a mandated outcome measure for clinical trials in rheumatoid arthritis and some other diseases.

The HAQ was developed as a comprehensive measure of outcome in patients with a wide variety of rheumatic diseases, including rheumatoid arthritis, osteoarthritis, juvenile rheumatoid arthritis, lupus, scleroderma, ankylosing spondylitis, fibromyalgia, and psoriatic arthritis. It has also been applied to patients with HIV/AIDS and in studies of normal aging. It should be considered a generic rather than a disease-specific instrument. Its focus is on self-reported patient-oriented outcome measures, rather than process measures.

Abbreviated Name: HAQ
Author(s): James F Fries
Purpose: To assess the difficulty in performing activities of daily living (Originally designed for adult arthritics, it has been used in a wide range of research settings)
Population: Adult
Age Range : 18 years and older
Type of Instrument: Disability/Physical functioning, Quality of Life
Mode of Administration:

Rater:	Self-/ Interviewer/ Telephone-administered
Time required:	HAQ Disability Index&Pain Scale: 5 mins / Full HAQ: 20 to 30 mins
Response Options:	Visual Analog Scale (VAS) for Pain and Global Health Assesment Four-item ordinal Scale for HAQ Disability Index from 0 (no disability) to 3 (completely disabled)
Scoring:	Global score: Minimum score: 0 / Maximum score: 3 Scores by dimension Scores by each item: from 0 (no disability) to 3 (completely disabled)
Score Direction:	Lower scores show better QoL (evident from each measure)

Number of Items: HAQ Disability Index: 20, Pain Scale: 1, Global Health Status: 1
Original Language: English
Existing Translations : Afrikaans, Arabic, Chinese, Croatian, Czech, Danish, Dutch, Finnish, French, German, Greek, Hebrew, Hungarian, Italian, Norwegian, Polish, Portuguese, Russian, Slovak, Spanish, Swedish, Thai, Turkish, Ukrainian.

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Contact for information and permission to use:

Judy Rechsteiner
Division of Immunology & Rheumatology
Stanford University School of Medicine
1000 Welch Rd.Suite 203
Palo Alto, CA 94304
Phone: 650/725-4612
Fax: 650/723-9656
Email: trex@stanford.edu

Dimensions covered by the questionnaire :

- dressing and grooming (2 items)
- arising (2 items)
- eating (3 items)
- walking (2 items)
- hygiene (3 items)
- reach (2 items)
- grip (3 items)
- activities (3 items)

Minimal Important Difference (MID): The HAQ index is very responsive to change, and usually is the most sensitive to change of the available outcome measures. It is used in the overwhelming majority of studies of rheumatoid arthritis and recommended by the United States Food and Drug Administration and the American College of Rheumatology. Some investigators have suggested that the Minimal Clinical Important Difference is 0.22; others have maintained that 0.10 or thereabouts is clinically important.

Key References:

1. Bruce B. and Fries J. The Stanford Health assesment Questionnaire (HAQ):A review of its history, issues, progress and documentation. J Rheumatol 2003;30(1):167-78.

Over the last 2 decades, assessment of patient health status has undergone a dramatic paradigm shift, evolving from a predominant reliance on biochemical and physical measurements to an emphaThesis upon health outcomes based on the patient's personal appreciation of their illness. Health Assessment Questionnaire (HAQ), published in 1980, was among the first instruments based on patient centered dimensions. The HAQ was designed to represent a model of patient oriented outcome assessment and has played a major role in diverse areas such as prediction of successful aging, inversion of the therapeutic pyramid in rheumatoid arthritis (RA), quantification of nonsteroidal antiinflammatory drug gastropathy, development of risk factor models for osteoarthrosis, and examination of mortality risks in RA. The HAQ has established itself as a valuable, effective, and sensitive tool for measurement of health status. It has increased the credibility and use of validated self-report measurement techniques as a quantifiable set of hard data endpoints and has contributed to a new appreciation of outcome assessment. We review the development, content, and dissemination of the HAQ and provide reference sources for its uses, translations, and validations. We discuss contemporary issues regarding outcome assessment instruments relative to the HAQ's identity and utility. These include: (1) the issue of labeling instruments as generic versus disease-specific; (2) floor and ceiling effects in scales such as "disability"; (3) distances between values on scales; and (4) the continuing introduction of new measurement instruments and their potential effects.

2. Fries JF, Spitz P, Kraines RG, Holman HR. Measurement of patient outcome in arthritis. Arthritis Rheum 1980; 23:137-45.

A structure for representation of patient outcome is presented, together with a method for outcome measurement and validation of the technique in rheumatoid arthritis. The paradigm represents outcome by five separate dimensions: death, discomfort, disability, drug (therapeutic) toxicity, and dollar cost. Each dimension represents an outcome directly related to patient welfare. Quantitation of these outcome dimensions may be performed at interview or by patient questionnaire. With standardized, validated questions, similar scores are achieved by both methods. The questionnaire technique is preferred since it is inexpensive and does not require interobserver validation. These techniques appear extremely useful for evaluation of long term outcome of patients with rheumatic diseases.

3. Fries JF. The hierarchy of quality-of-life assessment, the Health Assessment Questionnaire (HAQ), and issues mandating development of a toxicity index. Control Clin Trials 1991; 12:106S-17S.

Health, as defined by the World Health Organization, encompasses the more redundant and cumbersome phrase "health-related quality of life." Valuations by patients naturally separate this entity into the primary dimensions of absence of death, disability, discomfort, drug toxicity, and destitution. These dimensions separate naturally into subdimensions, and the subdimensions into components, thus providing a hierarchy under which assessment of particular aspects of health may be placed. In the clinical trial situation, it is essential that all dimensions always be assessed and reported, because otherwise, misleading conclusions may be drawn. On the other hand, it is much less important which assessment instrument is chosen, or how much detail is assessed for each dimension. The Health Assessment Questionnaire (HAQ) has been developed under a hierarchical conceptual model and widely used; its characteristics are described. A new index for measurement of drug toxicity has been developed for the HAQ, and its crucial role in comparing treatments in a clinical trial discussed. Issues in reliably describing comparative drug toxicity are developed, a toxicity index presented, and some preliminary results and conclusions outlined. With the ability to quantitatively describe drug toxicity, health assessment becomes conceptually more complete.

THE HEALTH ASSESSMENT QUESTIONNAIRE©
Stanford University School of Medicine
Division of Immunology & Rheumatology

INTRODUCTION

The Health Assessment Questionnaire (HAQ) was originally developed in 1978 by James F. Fries, MD, and colleagues at Stanford University. It was one of the first self-report functional status (disability) measures and has become the dominant instrument in many disease areas, including arthritis. It is widely used throughout the world and has become a de facto mandated outcome measure for clinical trials in rheumatoid arthritis and some other diseases.

The initial paper, published in 1980 (see key journal references at end of this document), has been the most cited article in the rheumatology literature. A 1995 review discusses more than 200 publications on the reliability, validity, and its applicability in multiple settings and languages. The present number of citations is in excess of 400.

Purpose

The HAQ was developed as a comprehensive measure of outcome in patients with a wide variety of rheumatic diseases, including rheumatoid arthritis, osteoarthritis, juvenile rheumatoid arthritis, lupus, scleroderma, ankylosing spondylitis, fibromyalgia, and psoriatic arthritis. It has also been applied to patients with HIV/AIDS and in studies of normal aging. It should be considered a generic rather than a disease-specific instrument. Its focus is on self-reported patient-oriented outcome measures, rather than process measures.

User Permission

The HAQ is copyrighted only so that it will be used unmodified, thus preserving the validity of results, and so that we retain a record of use. However, we consider the HAQ to be in the public domain, with the request that users cite relevant HAQ articles(s) in their publications (see key journal references at the end of this document). There is no charge for permission.

The "FULL" HAQ

Long term outcome assessment best includes the Full five-dimension HAQ, which is a comprehensive outcome instrument that assesses a hierarchy of patient outcomes in four domains: 1) disability, 2) discomfort and pain, 3) drug side effects (toxicity) and 4) dollar costs. Specific drug-associated side effects are classified according to their severity and whether the drug was stopped. Dollar costs are divided into direct and indirect costs. Direct costs include hospitalization, surgery, nursing home care, physician and health worker visits, medications, laboratory tests, x-rays, aids and devices, non-traditional treatments, assistance with personal care, housework and such, transportation and any additional costs related to medical care. Utilization of these services is determined and converted into dollar costs. Indirect costs are those associated with productive days lost for the employed, housewives, students and retired persons, and changes in lifestyle and activities for the patient and family.

Items address normal daily activities, employment status, marital status, and living arrangements. Death, while obviously not a self-report outcome, is a requisite part of the conceptual model of patient outcome. In the United States, this is usually accomplished using the National Death Index.

The first two domains, often referred to as "The HAQ", the "short" or the "2-page" HAQ, comprise the HAQ Disability Index (HAQDI) and Pain Scale. They can be used independently, frequently are and have been maintained as constant since 1983. The additional domains included in the Full HAQ (e.g., drug side effects [toxicity], dollar costs, plus other ancillary items such as demographics and health care utilization) have primarily been used for research purposes. These have over the years been tailored for specific hypotheses or research questions by ARAMIS (Arthritis, Rheumatism, and Aging Medical Information System).

The time frames differ among the various sections in the Full HAQ. Data on disability and pain are based on the PAST WEEK; for medications, symptoms, side effects and costs, data is based on the PAST SIX MONTHS.

QUESTIONNAIRE ADMINISTRATION

The HAQ is usually self-administered, but can also be given face-to-face in a clinical setting or in a telephone interview format by trained outcome assessors, and has been validated in these settings. The questionnaire is typically mailed to patients every six months, and they are asked to complete it without additional instructions. Follow-up phone calls are sometimes needed to obtain missing data or to clarify ambiguous responses in the high-quality research data applications. The HAQDI and Pain Scale can be completed in approximately five minutes. The Full HAQ takes 20 to 30 minutes to complete.

THE HAQDI

The HAQ indicates the extent of the respondent's functional ability. It has been widely used for research purposes in both experimental and observational studies, as well as in clinical settings. The HAQDI is sensitive to change and is a good predictor of future disability and costs. It has been shown to be reliable and valid in different languages and contexts. Test-retest correlations have ranged from 0.87 to 0.99. Correlations between interview and questionnaire format have ranged from 0.85 to 0.95. Validity has been demonstrated in literally hundreds of studies. There is consensus that the HAQDI possesses face and content validity. Correlations between questionnaire or interview scores and task performance have ranged from 0.71 to 0.95 demonstrating criterion validity. The construct/convergent validity, predictive validity and sensitivity to change have also been established in numerous observational studies and clinical trials. The HAQDI has also demonstrated a high level of convergent validity based on the pattern of correlations with other clinical and laboratory measures.

The HAQDI is designed to assess patients' USUAL abilities using their usual equipment. The time frame for the disability questions is the PAST WEEK. Some patients have questioned whether their response should reflect a particularly good or bad time, which is out of the time frame requested, because they feel that their response may be missing those times when their functional ability changes. However, by repeating the HAQ at specific and

regular time intervals, patterns of function can be examined. Inquiring about these activities only when patients are feeling particularly good or bad would result in inaccurate and biased data. The score is not modified if they have difficulties sometimes or require help only occasionally. Patients usually find the HAQDI entirely self-explanatory, and clarifications are seldom required.

Infrastructure

Disability is assessed by eight categories:

1) Dressing and Grooming	5) Hygiene
2) Arising	6) Reach
3) Eating	7) Grip
4) Walking	8) Common Daily Activities

For each of these categories, patients report the amount of difficulty they have in performing two or three specific sub-category items, or also known as components, or component variables.

The following conventions are used:

- Patients are instructed to respond idiomatically, using their own frame of reference. Thus, the ratings, SOME, MUCH, or USUAL, are deliberately not operationalized. For example, if a patient asks what "SOME" means, an appropriate response would be "Whatever you think 'SOME' means to you".

- If a sub-category item does not apply to a patient, e.g., they don't shampoo their hair, take tub baths, or reach for a heavy object above their heads, then they should leave the item(s) blank since the purpose is to obtain data about what they can do.

- If a patient uses aids or devices (e.g., clothing, faucets, cars), then they should answer the questions based on their usual equipment or way of performing the activity. If they have no difficulty with a sub-category item when using aids or devices (see below), then they mark the "no difficulty" column.

- If an individual can open their own door but not for others, then they should respond in consideration of their own requirements.

- When to the item about walking distance, patients should be advised to make their own decisions.

Scoring
There are four possible responses for each sub-category item within a category:

0 = without ANY difficulty

1 = with SOME difficulty

2 = with MUCH difficulty

3 = UNABLE to do

Conventions:

- If a sub-category item is left blank or the response is too ambiguous to assign a score, then the score for that category is determined by the remaining completed categories.
- If the respondent's mark is between the response columns, then the score is the closest one. If it's directly between the two, use the higher one
- If all sub-category items are left blank, or if more than one response is given, then follow up with the patient is required.

Calculating the HAQDI

To calculate the HAQDI, the patient must have score for at least 6 of the 8 categories. To calculate:

1. Add together the scores for the 8 categories* *(must be a minimum of 6 categories)*

*A category score is determined from the highest score of the sub-categories in that category, *except when aids or devices are taken into account* (see below). For example, if there are three sub-category items (e.g., in the category ARISING), and the patient responds 1, 2, and 0, respectively, to the three sub-category items, the score for the ARISING category will be a 2.

2. Divide by the number of categories answered (range - 6-8)
This yields a single disability index from 0-3 that indicates the extent of the respondent's functional limitations.

The scoring variables and scoring rules permit the computation of two disability indices, the Standard Disability Index, which takes into account the use of aids and devices, and the Alternative Disability Index, which does not. For either of these, a disability index cannot be computed if the patient does not have scores for at least 6 of the 8 categories.

1) The Standard Disability Index.

"What is the Disability level of this person?"

The Standard Disability Index, or commonly referred to as the HAQDI, takes into account the patient's use of aids or devices or assistance in the scoring algorithm for a category.

Use of AIDS OR DEVICES and/or HELP FROM ANOTHER PERSON

For each of the eight disability categories there is an AIDS OR DEVICES companion variable(s) that is used to record the type of assistance, if any, a patient uses for his/her usual activities.

HAQDI Category	Companion AIDS OR DEVICES
DRESSING & GROOMING	Devices used for dressing (button hook, zipper pull, long handled shoe horn etc.)
ARISING	Built up or special chair
EATING	Built up or special utensils
WALKING	Cane walker, crutches
HYGIENE	Raised toilet seat, bathtub seat, bathtub bar
	Long handled appliances in bathroom
REACH	Long handled appliances for reach
GRIP	Jar opener (for jars previously opened.

Devices written in the "Other" sections or notes written next to any component questions are considered if they would be used for any of the stated categories. Permanent adaptations of the person's environment (e.g., changing faucets in the bathroom or kitchen, using Velcro closures on clothing) should also be counted as aids and devices.

In the ARAMIS experience, very few patients have reported other items, and when they have, it has usually been either a duplicate of an aid or device already on the list or they have listed something that does not count (e.g., a wrist splint). Thus, it is acceptable to exclude the "Other" option if desired.

Scoring AIDS OR DEVICES or help companion variables:

1. When there are **NO** aids or devices or help indicated for a category, the category's score is not modified.

2. When aids or devices and/or help **ARE** indicated by the patient, the score for the category item is raised from a 0 or 1 to a 2, but if the patient's highest score for that sub-category is a 3, it stays a 3.

The assignment of devices to particular disability categories assumes that the devices are used only for their intended purposes, such that if a patient indicates that he/she uses a cane, it is presumed that they use the cane as an aid in walking. However, it is possible for that patient to use the cane as an aid in performing other activities. For example, the patient may check off the cane listed at the bottom of the page (or write "cane" under the "other" slot) and then write a little note in the margin stating that the cane is also used on a regular basis as an aid in helping them rise out of a chair and to rise off of the toilet. In such a case, the variables should be coded as "1" to reflect the patient's use of a cane in these three areas of daily

functioning. If unsure whether the patient is using one of the devices specified above for the purpose for which it is designed, the patient should be called for clarification of specific uses.

2) The Alternative Disability Index.

"What is the disability level when using aids and devices to compensate for disability?"

The Alternative Disability Index is calculated without taking into account the use of AIDS OR DEVICES. It is calculated by adding the scores for each of the categories and dividing by the number of categories answered. This yields a score between 0 to 3.0.

Using the Standard HAQDI vs the Alternative Disability Index Scoring Method

There are specific circumstances where the alternative score would be preferable. For example, in an investigation where a goal is to increase the use of aids and devices, if aids and devices were taken into account, scoring would be biased and findings would indicate that the study increased HAQ disability scores.

The Pain Scale

Discomfort is determined by the presence of pain and its severity.
The pain scale is designed to obtain data relative to the presence or absence of arthritis-related pain and its severity. The reference time frame is THE PAST WEEK. The objective is to obtain information from patients on how their pain has USUALLY been over the past week, even though pain may be reported to vary over the course of a day or from day to day.

Scoring Conventions for the Pain Scale:

Pain is measured on a doubly-anchored visual analog scale (a horizontal line where each end represents opposite ends of a continuum) that is standardized to 15 centimeters in length; the length is convenient for the page and for the patient. It is labeled with "no pain" (with a score of 0) at one end and "very severe pain" (with a score of 100 at the other). Patients are instructed to place a vertical mark on the line to indicate the severity of their pain. A score from 0 to 3 is obtained based on the location of the respondent's mark.

To obtain the individual's score, with a metric ruler, measure the distance in centimeters from the left side (at base zero) of the line up to the mark and multiply by 0.2. This converts the number of centimeters into the appropriate score and will yield a value from 0 to 3.

Some potential scenarios and scoring conventions:

- If the patient writes in a number on the pain scale, or writes a number in addition to making a mark, take the number, converting it to the corresponding score. In this care, do not measure the mark. For example, if the patient writes "50" on the line, this should be coded as 1.5.

- If an individual records a percentage, multiply the percentage by 3. Pain severity coding translations follow below: If a patient puts more than one mark, the midpoint is used.

- If a patient makes a horizontal line below the pain scale, instead of a vertical one, the midpoint of that line is taken. If the line starts at the beginning of the scale, measure to the end of the line not the middle.

A 0-100 mm scale may be used, which requires no score computation.

PAIN SEVERITY CODING TRANSLATIONS

Measurement (m) = Score	***Measurement (m) = Score [contd]***
0 = 0	7.8 - 8.2 = 1.6
0.1 - 0 .7 = 0.1	8.3 - 8.7 = 1.7
0.8 - 1.2 = 0.2	8.8 - 9.2 = 1.8
1.3 - 1.7 = 0.3	9.3 - 9.7 = 1.9
1.8 - 2.2 = 0.4	9.8 - 10.2 = 2.0
2.3 - 2.7 = 0.5	10.3 - 10.7 = 2.1
2.8 - 3.2 = 0.6	10.8 - 11.2 = 2.2
3.3 - 3.7 = 0.7	11.3 - 11.7 = 2.3
3.8 - 4.2 = 0 .8	11.8 - 12.2 = 2.4
4.3 - 4.7 = 0 .9	12.3 - 12.7 = 2.5
4.8 - 5.2 = 1.0	12.8 - 13.2 = 2.6
5.3 - 5.7 = 1.1	13.3 - 13.7 = 2.7
5.8 - 6.2 = 1.2	13.8 - 14.2 = 2.8
6.3 - 6.7 = 1.3	14.3 - 14.7 = 2.9
6.8 - 7.2 = 1.4	14.8 - 15.0 = 3.0

Drug Side Effects [Toxicity]

A prevalence of symptom frequency is obtained by inquiring about symptoms, conditions, and side effects that have occurred in the past six months. Data on side effects associated with specific drugs includes severity of side effects, whether or not the drug was stopped, and importance of the side effects to the patient. These items about patient-attributed drug side effects provide the six-month incidence figures. Scoring and coding: For additional information, please contact us.

Dollar Cost And Other Items - For additional information, please contact us.

KEY JOURNAL REFERENCES

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HEALTH ASSESSMENT QUESTIONNAIRE©

Stanford University School of Medicine

Division of Immunology & Rheumatology

Name_____ **Date**_____

In this section we are interested in learning how your illness affects your ability to function in daily life. Please feel free to add any comments on the back of this page.

Please check the response which best describes your usual abilities OVER THE PAST WEEK:

	Without ANY difficulty [0]	With SOME difficulty [1]	With MUCH difficulty [2]	UNABLE to do [3]
DRESSING & GROOMING				
Are you able to:				
-Dress yourself, including tying shoelaces and doing buttons?	☐	☐	☐	☐
-Shampoo your hair?	☐	☐	☐	☐
ARISING				
Are you able to:				
-Stand up from a straight chair?	☐	☐	☐	☐
-Get in and out of bed?	☐	☐	☐	☐
EATING				
Are you able to:				
-Cut your meat?	☐	☐	☐	☐
-Lift a full cup or glass to your mou	☐	☐	☐	☐
-Open a new milk carton?	☐	☐	☐	☐
WALKING				
Are you able to:				
-Walk outdoors on flat ground?	☐	☐	☐	☐
-Climb up five steps?	☐	☐	☐	☐

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Please check any AIDS OR DEVICES that you usually use for any of these activities:

- ☐ Cane
- ☐ Walker
- ☐ Crutches
- ☐ Wheelchair
- ☐ Devices used for dressing (button hook, zipper pull, long-handled shoe horn, etc.)
- ☐ Built up or special utensils
- ☐ Special or built up chair
- ☐ Other (Specify:_____)

Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

- ☐ Dressing and Grooming
- ☐ Arising
- ☐ Eating
- ☐ Walking

Full HAQ-Ph 37

Please check the response which best describes your usual abilities **OVER THE PAST WEEK:**

	Without ANY difficulty [0]	With SOME difficulty [1]	With MUCH difficulty [2]	UNABLE to do [3]
HYGIENE				
Are you able to:				
-Wash and dry your body?	☐	☐	☐	☐
-Take a tub bath?	☐	☐	☐	☐
-Get on and off the toilet?	☐	☐	☐	☐
REACH				
Are you able to:				
-Reach and get down a 5-pound object (such as a bag of sugar) from just above your head?	☐	☐	☐	☐
-Bend down to pick up clothing from the floor?	☐	☐	☐	☐
GRIP				
Are you able to:				
-Open car doors?	☐	☐	☐	☐
-Open jars which have been previously opened?	☐	☐	☐	☐
-Turn faucets on and off?	☐	☐	☐	☐
ACTIVITIES				
Are you able to:				
-Run errands and shop?	☐	☐	☐	☐
-Get in and out of a car?	☐	☐	☐	☐
-Do chores such as vacuuming or yardwork	☐	☐	☐	☐

Please check any AIDS OR DEVICES that you usually use for any of these activities:

☐ Raised toilet seat
☐ Bathtub seat
☐ Jar opener (for jars previously opened)
☐ Bathtub bar
☐ Long-handled appliances for reach
☐ Long-handled appliances in bathroom
☐ Other (Specify:_____)

Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

- ☐ Hygiene
- ☐ Gripping and opening things
- ☐ Reach
- ☐ Errands and chores

We are also interested in learning whether or not you are affected by pain because of your illness.

How much pain have you had because of your illness IN THE PAST WEEK:

PLACE A VERTICAL (|) MARK ON THE LINE TO INDICATE THE SEVERITY OF THE PAIN

NO PAIN — SEVERE PAIN

0 100

1. Have you participated in any clinical trials in the **PAST 6 MONTHS?**

   ☐ No

   ☐ Yes - trial of an arthritis medicine Name of medicine _____

   ☐ Yes - trial of another type of medicine Name of medicine _____

   ☐ Don't know the name of the medicine

2. In general, would you say your current health is:

   ☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor

SYMPTOMS

1. Please check any items which apply to your health during the **PAST 6 MONTHS.**

If *none*, check here: ☐

HEAD, EYES, EARS, NOSE, MOUTH AND THROAT:
- ☐ Blurred vision
- ☐ Ringing in ears
- ☐ Hearing difficulties
- ☐ Mouth sores
- ☐ Loss, change in taste
- ☐ Headache
- ☐ Dizziness
- ☐ Fever

CHEST, LUNGS AND HEART
- ☐ Chest pain
- ☐ Shortness of breath
- ☐ Wheezing (asthma)

GASTROINTESTINAL TRACT:
- ☐ Loss of appetite
- ☐ Nausea
- ☐ Heartburn
- ☐ Indigestion or belching
- ☐ Pain or discomfort in upper abdomen(stomach)
- ☐ Liver problems, kind_____ _____
- ☐ Pain or cramps in lower abdomen (colon)
- ☐ Diarrhea (frequent, explosive watery bowel movements, severe)
- ☐ Constipation
- ☐ Black or tarry stools (not from iron)
- ☐ Vomiting

MUSCULOSKELETAL:
- ☐ Joint pain
- ☐ Joint swelling
- ☐ Low back pain
- ☐ Muscle pain
- ☐ Neck pain
- ☐ Weakness of muscles
- ☐ If you are stiff in the morning _____(hr/min) how long does the stiffness last?

NEUROLOGIC AND PSYCHOLOGIC
- ☐ Depression
- ☐ Insomnia
- ☐ Nervousness
- ☐ Tiredness (Fatigue)
- ☐ Trouble thinking or remembering

SKIN:
- ☐ Easy bruising
- ☐ Hives or welts
- ☐ Itching
- ☐ Rash

FEMALES ONLY - ☐ Are you pregnant?

OTHER
- ☐ Any others? (specify)_____

MEDICATIONS

1. In the **PAST 6 MONTHS** have you taken any medications? ☐ Yes ☐ No

Please complete **ALL THE BLANKS ON THE LINE** for any medications that you have taken. If a medication is taken **occasionally or as needed**, please estimate the **number of days per month** you have taken it. **IF RECORDING ASPIRIN**, please note regular or enteric coated.

For the last column "OVERALL SATISFACTION", considering both effectiveness and side effects, please rate your satisfaction with each drug as a treatment for your arthritis on a scale of 0 - 10 where "0" means you were Totally dissatisfied and "10" means you were Extremely satisfied.

ARTHRITIS MEDICATIONS TAKEN BY MOUTH (both prescription and over-the-counter) ***INCLUDE OCCASIONAL or AS NEEDED MEDICATIONS***	Number of pills per day	Mg. Per Pill	**Still taking** PLEASE CHECK (√)	Number of **months** out of last 6 months on drug	If **Started or Stopped** in Last 6 Months, List month and year **Started / Stopped**		**Overall Satisfaction** as a Treatment for your arthritis [0 - Totally dissatisfied to 10 - Extremely satisfied]

If you are taking Prednisone, how are you taking it? (e.g. every other day/once per day/twice per day/other) _____

MEDICATIONS TAKEN BY INJECTION OR IN VEIN (IV) (e.g., gold salt injections, steroid injections, Enbrel, Remicade)	Total Number of Treatments in the Last 6 Months	**Still Taking** PLEASE CHECK (√)	Number of **Months** out of Last 6 Months on Drug	If **Started or Stopped** in Last 6 Months, List Month and Year **Started Stopped**		**Overall Satisfaction** as a Treatment For Your Arthritis[0 -Totally dissatisfied to 10 - Extremely satisfied]

OTHER MEDICATIONS Please list **all** other medications (both prescription and over-the-counter) you have taken in the **PAST 6 MONTHS** for any other medical condition. ***INCLUDE OCCASIONAL or AS NEEDED MEDICATIONS***	Number of Pills Per Day	Mg. Per Pill	**Still Taking** PLEASE CHECK (√)	Number of **Months** out of Last 6 Months on Drug	If **Started or Stopped** in Last 6 Months, List Month and Year **Started**	**Stopped**
For additional medications, please use the comment section at the end of the questionnaire						

2. We are interested in finding out about your experience with **pain medications taken on an occasional basis**. "Occasional use" means you take at least a couple of tablets in 6 months, but you do not take the medication daily for periods of more than a month. We would like to find out about occasional use of **aspirin** (e.g., Bayer, Ecotrin, Bufferin), **acetaminophen** (e.g., Tylenol), and **ibuprofen** (e.g., Advil, Motrin) for headaches and minor aches and pains.

ASPIRIN (e.g., Bayer, Ecotrin, Bufferin)	**1990 - 1998**	**Past 6 months**
Have you taken **aspirin** on an occasional basis during this time period?	☐ Yes ☐ N	☐ Yes ☐ No
If yes, how many days in a typical month do you take it?	_____	_____
On the days when you are taking it, on average, how many tablets do you take?	_____	_____

When you take **aspirin** occasionally, why do you take it?

☐ Headaches ☐ Muscle aches and pains ☐ Menstrual cramps

☐ Other, specify _____

When you take **aspirin** occasionally, do you have any side effects? ☐ Yes ☐ No

If yes, what types of side effects have you had?

_____

ACETAMINOPHEN (e.g., Tylenol)	**1990 - 1998**	**Past 6 months**
Have you taken **acetaminophen** on an occasional basis during this time period?	☐ Yes ☐ N	☐ Yes ☐ No
If yes, how many days in a typical month do you take it?	_____	_____
On the days when you are taking it, on average, how many tablets do you take?	_____	_____

When you take **acetaminophen** occasionally, why do you take it?

☐ Headaches ☐ Muscle aches and pains ☐ Menstrual cramps

☐ Other, specify ___

_____

When you take **acetaminophen** occasionally, do you have any side effects? ☐ Yes ☐ No

If yes, what types of side effects have you had? _____

IBUPROFEN (e.g., Advil, Motrin)	**1990 - 1998**	**Past 6 months**
Have you taken **ibuprofen** on an occasional basis during this time period?	☐ Yes ☐ No	☐ Yes ☐ No
If yes, how many days in a typical month do you take it?	_____	_____
On the days when you are taking it, on average, how many tablets do you take?	_____	_____

When you take **ibuprofen** occasionally, why do you take it?

☐ Headaches ☐ Muscle aches and pains ☐ Menstrual cramps

☐ Other, specify _____

When you take **ibuprofen** occasionally, do you have any side effects? ☐ Yes ☐ No

If yes, what types of side effects have you had? _____

3.Did you stop taking any **ARTHRITIS MEDICINES** during the **PAST 6 MONTHS**, regardless of reason? ☐ Yes ☐ No

If Yes, please tell us below what medicines you stopped, why you stopped, and tell us about the medicine you are now taking instead. (These medications should also be listed on the Medication page)

Name of Drug You Stopped Please Print	If Stopped, Why? (X all that apply)	Did You Start Another Medicine to Replace it? **Yes** **No**	If Yes, Which Medicine? Please Print
1.	Didn't work Side Effects Other	☐ ☐	
2.	Didn't work Side Effects Other	☐ ☐	
3.	Didn't work Side Effects Other	☐ ☐	
4.	Didn't work Side Effects Other	☐ ☐	

Although you have already listed your medications, please answer the following items which request additional information about certain kinds of medications.

4. In the **PAST 6 MONTHS**, have you taken any "health food" type supplements? (Examples: glucosamine, chondroitin, vitamins, herbs) ☐ Yes ☐ No
   If Yes, please tell us about them in the table below:

Supplement	Number of Tablets per Day	Mg. (or Units) per Tablet	Number of **Months** Taken in Last 6 Months	If Still Taking Please Check (√)

5. a. Have you had any of the following injections in your joints in the **PAST 6 MONTHS**? We are interested in injections of a new material, similar to natural joint fluid, that acts as a lubricant and shock absorber for the joints.

☐ None ☐ Synvisc (Hylan G-F20) ☐ Hyalgan (Sodium Hyaluronate) ☐ Don't Know

b. Which joints were injected with the above drug?
☐ None
☐ Both Knees
☐ One Knee
☐ Other[5], Specify _____

c. What is the total number of injections you have had, counting both knees? _____ _____

6. Have you EVER used **ACETAMINOPHEN** (Tylenol) for your arthritis? ☐ Yes ☐ No

a. If Yes, please indicate on a scale of 0 to 10, how satisfied you were with acetaminophen as a treatment for your arthritis.

"0" means you were totally dissatisfied and "10" means you were extremely satisfied.

|----------|
0 10
Totally dissatisfied Extremely satisfied

b. We would like you to compare your experience with acetaminophen (Tylenol) to your experience with anti-inflammatory drugs (such as ibuprofen, Naprosyn, Relafen, Lodine, Celebrex, Daypro, etc.). Thinking only about the effectiveness of acetaminophen, was it:

|----------|
0 10
Much less effective Much more effective

c. Now, taking into consideration both **effectiveness** AND any **side effects** that you experienced with either type of drug, please compare your OVERALL SATISFACTION with acetaminophen to that of anti-inflammatory drugs you have taken. Was the acetaminophen:

|----------|
0 10
Much less satisfactory Much more satisfactory

7. In the **PAST 6 MONTHS**, have you taken **Coumadin (Warfarin)** ? ☐ Yes ☐ No

8. Have you taken any of the following medications in the **PAST 6 MONTHS?** ☐ Yes ☐ No

If Yes, indicate number of months for each medication you have taken.

Medication	**Number** of Months Taken Out of **Past 6 Months**
Vitamin D supplements	
Calcium	

Fluoride	
Estrogens (female hormone replacement therapy)	
Osteoporosis drugs, specify:_____	

DRUG SIDE EFFECTS

Have you had any side effect(s) from your medication in the **PAST 6 MONTHS** ☐ Yes ☐ No

COMPLETE THE REST OF THIS SECTION ONLY IF YOU HAVE SAID YES.

DIRECTIONS:

1. Write in the name of the drug causing the side effect(s).
2. Indicate whether you stopped the drug.
3. List side effect(s) for each drug. You may want to refer back to page 3. Please list any abnormal laboratory findings such as: low white blood count, protein in urine, low platelets, kidney problems, anemia,liver problems.
4. Check the severity of each side effect.
5. **Please indicate how important the side effect was to you by making a mark on the scale from 0 to 10, where 0 is Not At All and 10 is Very Much.**
6. If you need more room, please use the back of this questionnaire.

A. (1) DRUG NAME_____

(2) Did you STOP the drug because of a side effect? ☐ Yes ☐ No

(3) LIST SIDE EFFECT _____

(4) SEVERITY of side effect ☐ mild ☐ moderate ☐ severe

(5) How important was this side effect to you?

0 10

|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|

Not at All Very Much

B. (1) DRUG NAME_____

(2) Did you STOP the drug because of a side effect? ☐ Yes ☐ No

(3) LIST SIDE EFFECT _____

(4) SEVERITY of side effect ☐ mild ☐ moderate ☐ severe

(5) How important was this side effect to you?

0 10

|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|

Not at All Very Much

C. (1) DRUG NAME_____

(2) Did you STOP the drug because of a side effect? ☐ Yes ☐ No

(3) LIST SIDE EFFECT _____

(4) SEVERITY of side effect ☐ mild ☐ moderate ☐ severe

(5) How <u>important</u> was this side effect to you?

0 10

|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|

Not at All Very Much

D. (1) DRUG NAME_____

(2) Did you STOP the drug because of a side effect? ☐ Yes ☐ No

(3) LIST SIDE EFFECT _____

(4) SEVERITY of side effect ☐ mild ☐ moderate ☐ severe

(5) How important was this side effect to you?

0 10
|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------
|
Not at All Very Much

E. (1) DRUG NAME_____

(2) Did you STOP the drug because of a side effect? ☐ Yes ☐ No

(3) LIST SIDE EFFECT _____

(4) SEVERITY of side effect ☐ mild ☐ moderate ☐ severe

(5) How important was this side effect to you?

0 10
|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------
|
Not at All Very Much

F. (1) DRUG NAME_____

(2) Did you STOP the drug because of a side effect? ☐ Yes ☐ No

(3) LIST SIDE EFFECT _____

(4) SEVERITY of side effect ☐ mild ☐ moderate ☐ severe

(5) How important was this side effect to you?

0 10
|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------
|
Not at All Very Much

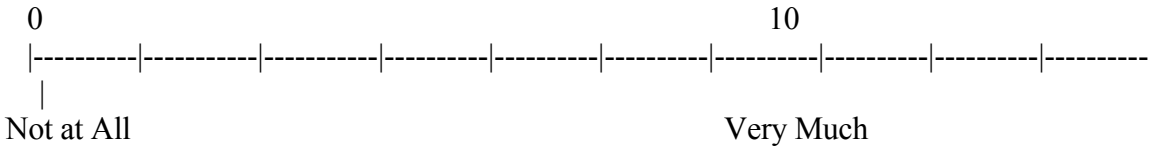
G. (1) DRUG NAME_____

(2) Did you STOP the drug because of a side effect? ☐ Yes ☐ No

(3) LIST SIDE EFFECT _____

(4) SEVERITY of side effect ☐ mild ☐ moderate ☐ severe

(5) How <u>important</u> was this side effect to you?



MEDICAL HISTORY

We are interested in your use of health care providers in the **PAST 6 MONTHS.** Please include **ALL** visits.

1. In the **PAST 6 MONTHS** did you stay in the hospital overnight for any reason? ☐ Yes ☐ No

   -If Yes, please describe each hospitalization visit:

Reason for Hospitalization	Hospital (City, State)	Admission Date (Month, Year)	Number of Nights in Hospital	Was this a Medical or Surgical Stay?

2. Were any of these hospitalizations related to a side effect from any of your medications? ☐ Yes ☐ No

   -If Yes, which hospitalization(s) and which medication(s):_____

   _____

3. In the **PAST 6 MONTHS** have you had any outpatient surgery or procedures? ☐ Yes ☐ No

   -If Yes, please list:

Surgery/ Procedure	Doctor's Name	Location and Address (Hospital, Doctor's Office)	Date (Month, Year)	Was this a Medical or Surgical Visit?

4. In the **PAST 6 MONTHS** have you been to a hospital Emergency Room? ☐ Yes ☐ No

   Do not include "after hour clinics" or "urgent care centers"

   -If Yes**,** how many visits? _____

5. In the **PAST 6 MONTHS** were you a patient in a nursing or convalescent home or live-in rehabilitation center?

☐ Yes ☐ No

-If Yes, for how many days? _____ Days

6.Have you seen any doctors or any other health workers in the **PAST 6 MONTHS?**
☐ Yes ☐ No
DO NOT INCLUDE ANY WHILE A PATIENT IN THE HOSPITAL.

-If Yes, please complete

	NUMBER of visits In Last 6 Months
Rheumatologist	_____
Internist	_____
Family physician (general practitioner)	_____
Nurse practitioner/physician assistant	_____
Gastroenterologist	_____
Urologist/proctologist	_____
General or orthopedic surgeon	_____
Podiatrist (foot doctor)	_____
Chiropractor	_____
Physical or occupational therapist	_____

Other doctors (dermatologist or others)
Please specify:

_____

_____

Other Health Workers (Social worker or others)

_____ _____

_____ _____

Diagnostic Procedures

7. Have you had any diagnostic tests or treatments in the **PAST 6 MONTHS?** ☐ Yes ☐ No

DO NOT INCLUDE ANY THAT WERE DONE WHILE YOU WERE A PATIENT IN THE HOSPITAL

-If Yes, please complete the following.

	NUMBER of tests	**Part of body**
X-Rays (chest, stomach or bowels, joints, etc.)	_____	_____
Nuclear Medicine Scans (Bone scan) or Magnetic Resonance Imaging (MRI)	_____	
_____		
CT Scan	_____	
_____		

Blood tests (Number of times blood was drawn)_____

_____

Urine tests ..... _____ _____

Endoscopy (Gastroscopy) ..... _____ _____

Colonoscopy ..... _____ _____

Other tests, please specify _____

MEDICAL CONDITIONS

1. Have you been diagnosed with any **NEW** medical problems in the **PAST 6 MONTHS?**
☐ Yes ☐ No

If yes, please complete the following:

High blood pressure	☐ Yes ☐ No	Lung problem	☐ Yes ☐ No
Other Heart Conditions	☐ Yes ☐ No	Cataract	☐ Yes ☐ No
Stroke	☐ Yes ☐ No	Ulcers/stomach problems	☐ Yes ☐ No
Depression	☐ Yes ☐ No	Asthma	☐ Yes ☐ No
Mental Illness	☐ Yes ☐ No	Liver Problems	☐ Yes ☐ No
Diabetes	☐ Yes ☐ No	Thyroid or Endocrine problems	
Cancer	☐ Yes ☐ No	Parkinson's)	☐ Yes ☐ No
Alcohol or drug problems	☐ Yes ☐ No		

2. We are interested in finding out if you have ever had certain kinds of **heart and circulation problems**, since arthritis may affect the risk of these conditions. Your answers will help us determine whether some types of problems occur more or less frequently in patients with arthritis.

Have you **ever** had any of the following problems?	☐ Yes ☐ No	Year: _____
Heart attack / myocardial infarction (MI)	☐ Yes ☐ No	Year: _____
Angina (chest pain due to heart disease)	☐ Yes ☐ No	Year: _____
Coronary Artery Bypass Surgery	☐ Yes ☐ No	Year: _____
(CABG)	☐ Yes ☐ No	Year: _____
Balloon Angioplasty	☐ Yes ☐ No	Year: _____
Heart Catheterization	☐ Yes ☐ No	Year: _____
Congestive Heart Failure (CHF)	☐ Yes ☐ No	Year: _____
CHF currently being treated		
Heart Valve Problem		

3. Have you had any **INFECTIONS** in the **PAST 6 MONTHS**? DO NOT INCLUDE COLDS OR FLU
☐ Yes ☐ No

PLEASE INCLUDE EMERGENCY ROOM AND OUT-PATIENT VISITS

-If Yes, please answer the following:

	Number of Infections	**Number of emergency room or out-patient visits**	**Number of times admitted to the hospital**
☐ Septicemia (Sepsis, blood stream infection)	_____	_____	_____
☐ Pneumonia	_____	_____	_____
☐ Shingles (Herpes zoster)	_____	_____	_____
☐ Bone/Joint Infection (osteomyelitis, septic joint, infected artificial joint)	_____	_____	_____
☐ Skin infections (infected skin ulcer, Cellulitis, infected nodules)	_____	_____	_____
☐ Urinary tract infection/Kidney infection	_____	_____	_____
☐ Bladder infection	_____	_____	_____
☐ Other, specify	_____	_____	_____

4. How much trouble have you had with your **STOMACH** (i.e., nausea, heartburn, bloating, pain, etc.) in the past week?

Place a mark on the line below:

|----------|
0 100
No stomach problems — Severe stomach problems

If you had any stomach problems, were they related to a specific drug or drugs?

If yes, what drug(s)? _____

5 a. **IN THE PAST 6 MONTHS**, have you been told BY A PHYSICIAN that you had an ulcer ? (a stomach or duodenal ulcer) ☐ Yes ☐ No

b. Which of the following did he/she use to diagnose your ulcer? (Mark all that apply)

☐ Endoscopy ☐ X-ray ☐ Talking to you about your symptoms

Date of diagnosis _____

6. In the PAST 6 MONTHS, have you had a **BROKEN BONE (FRACTURE),** fractures of the spine or vertebrae, broken back, collapsed vertebrae, or been told you had a "fracture on x-ray"?

   ☐ Yes ☐ No

   If yes, please complete:

What bone was broken?	How did fracture occur?	What month did it occur?
_____	_____	_____
_____	_____	_____

7. In the PAST 6 MONTHS**,** have you been told that you had **OSTEOPOROSIS**, thinning of the bones, or lack of calcium in your bones?

   ☐ Yes ☐ No

8. In the **PAST 6 MONTHS** have you been diagnosed with a kidney or renal problem (do not include urinary tract or kidney infections)?

   ☐ Yes ☐ No

   -If Yes, please answer questions a - c

   a. What kind of kidney or renal problem did/do you have? _____
   b. Were you ever hospitalized for this problem? ☐ Yes ☐ No
   c. Did you have kidney dialysis in the PAST 6 MONTHS? ☐ Yes ☐ No

9. In the **PAST 6 MONTHS** have you been told that you have any kind of **TUMOR OR CANCER**?

☐ Yes ☐ No

-If yes, was it: ☐ Benign ☐ malignant

What kind? (for example: leukemia, lymphoma, lung) _____

10. Have you **EVER** been diagnosed with any kind of cancer? ☐ Yes ☐ No

-If Yes, What kind? _____ What year was it diagnosed? _____

What kind? _____ What year was it diagnosed? _____

HEALTH STATUS

1. Considering all the ways that your arthritis affects you, rate how you are doing on the following scale by placing a mark on the line.

```
|-------------------------------------------------------------------------------|
0                                                                           100
very                                                                        very
well                                                                        poor
```

2. How satisfied are you with your HEALTH NOW?

☐ Very satisfied[1] ☐ Somewhat dissatisfied[4]
☐ Somewhat satisfied[2] ☐ Very dissatisfied[5]
☐ Neither satisfied or dissatisfied[3]

3. How tall are you? _____ Feet _____ Inches

4. How much do you weigh? _____ Pounds

HEALTH BEHAVIORS

1. Have you ever smoked cigarettes?

☐ No

☐ Yes, If yes, what year did you start smoking? _____

On average, how many packs per day have you smoked? _____ packs

Do you smoke now?

☐ No, If No, what year did you stop smoking? _____ ☐ Yes

2. Do you regularly drink alcoholic beverages? ☐ Yes ☐ No

If Yes, how many drinks do you usually have in a typical day?

_____ Beer (1 drink = 12 oz. can or bottle)

_____ Wine (1 drink = 6 oz. glass)

_____ Hard liquor, cocktails, or cordial (1 drink = 1 1/2 oz. liquor)

3. During a **typical week**, how much **total** time (for the **entire week**) do you spend on each of the following?

If *none*, check here: ☐

MINUTES PER WEEK

Stretching or strengthening exercise _____

Walk for exercise _____

Swimming or aquatic exercise _____

Bicycling (including stationary, exercise bikes) _____

Other aerobic exercise equipment (stair climber or skiing machines) _____

Other aerobic exercise, Specify_____ _____

BACKGROUND

1. Do you have access to the World Wide Web? At home? ☐ Yes ☐ No
At work? ☐ Yes ☐ No

If yes, during the past six months, about how often did you logon to the Internet / Web?

☐ Daily or almost daily ☐ 2-3 times per week ☐ 3-4 times per month ☐ Occasionally

Do you have e-mail? ☐ Yes ☐ No

If yes, during the past six months, about how often did you check your e-mail?

☐ Daily or almost daily ☐ 2-3 times per week ☐ 3-4 times per month ☐ Occasionally

If given a choice, how would you prefer to fill out your questionnaire?

☐ By US mail ☐ On a web site

2. What type(s) of **HEALTH INSURANCE** do you have?
(Please check all that apply)

☐ **None**

☐ **Medicaid / Medi-Cal** (State Assistance)

☐ **Medicare Part A** (Medicare insurance for hospital care)

☐ **Medicare Part B** (Medicare insurance for physician visits and other non-hospital care)

☐ **Medicare/HMO** (Insurance for people with Medicare who select to join a health maintenance organization, HMO)

Name of HMO: _____

☐ **Medigap Insurance** (Additional insurance for people covered by Medicare. Medigap policies generally pay the Medicare deductibles and co-insurance.

☐ **Medicare Disability Insurance**

☐ **Other public assistance Insurance**

☐ **Traditional Insurance** (Insurance where you may see any physician you choose. Many traditional insurance policies require you to pay coinsurance (a percentage of the charges for each visit) and/or a deductible)

Name: _____

☐ **Health Maintenance Organization (HMO)** (Insurance where you must see a primary care physician to receive care. In most cases, the primary care physician must authorize visits to specialists or other providers. Primary care physicians are chosen from a list of physicians affiliated with the organization. In most cases, HMOs charge a small copayment for each visit, but have no deductible.)

Name: _____

☐ **Preferred Provider Organization (PPO)** (Insurance where you may see any physician you choose, but you pay a different amount depending on whether or not the physician is affiliated with the organization and whether or not you are referred by your primary care physician)

Name: _____

☐ **Champus / VA**

☐ **Federal Employees Health Benefit Program**

EMPLOYMENT STATUS

1. Which one of the following categories best describes you at this time?

☐ Working for pay: Occupation_____
Job duties_____
Hours/week_____
Personal yearly earnings - nearest thousand (optional)_____
(NOT TOTAL HOUSEHOLD INCOME) I

☐ Retired

☐ Homemaker

☐ Student

☐ Disabled

☐ Looking for work

☐ On sick leave: Occupation_____

☐ On vacation: Occupation_____

☐ Other (Specify):_____

2. In the **PAST 6 MONTHS** have there been days when you have had to **CUT DOWN** or **LIMIT** your usual non-employment activities (including housework, school) **BECAUSE OF YOUR HEALTH**?

☐ Yes ☐ No

If yes, how many days? _____

3. IN THE **PAST 6 MONTHS** have there been days when you have been **COMPLETELY UNABLE** to carry out your usual non-employment activities **BECAUSE OF YOUR HEALTH**?

☐ Yes ☐ No

If yes, how many days? _____

IF YOU ARE <u>NOT</u> EMPLOYED, PLEASE SKIP TO THE LAST PAGE

IF YOU ARE EMPLOYED, PLEASE ANSWER QUESTIONS 4 - 8

4. IN THE **PAST 6 MONTHS** have you missed any days of work **BECAUSE OF YOUR HEALTH**?

☐ Yes ☐ No

If yes, how many days? _____

5. In the **PAST 6 MONTHS** have there been any days when you were not able to do your regular work tasks **BECAUSE OF YOUR HEALTH**?

☐ Yes ☐ No

If Yes, how many days? _____

6. IN THE **PAST 6 MONTHS** have you stopped or started working **BECAUSE OF YOUR HEALTH**?

☐ Yes ☐ No

If Yes, please check (√):

☐ Stopped working: When? _____ Was it due to your arthritis? ☐ Yes ☐ No

☐ Started working: When? _____ Was it due to your arthritis? ☐ Yes ☐ No

7. IN THE **PAST 6 MONTHS** have you changed your **HOURS** of work **BECAUSE OF YOUR HEALTH**?

☐ Yes ☐ No

If Yes, please check (√):

☐ Increased hours Was it due to your arthritis? ☐ Yes ☐ No

☐ Decreased hours Was it due to your arthritis? ☐ Yes ☐ No

8. In the **PAST 6 MONTHS** have you taken <u>unpaid</u> time off from work to visit your doctor, a psychologist, or other health professional?

☐ Yes ☐ No

-If yes, how many hours have you taken off? _____ hours/past 6 months

COMMENTS:

This page asks you for permission to allow us to review medical records pertaining to your involvement in this research program. This information will be kept strictly confidential and used for research purposes only.

RELEASE OF MEDICAL INFORMATION

I give permission for the release of information pertaining to my medical/financial care to the ARAMIS Studies.

PLEASE USE INK

Name: _____
(PLEASE PRINT)

Address: _____

_____

_____
Postal/Zip Code

Date of Birth: _____

Please sign below:

Signature: _____

Date: _____

HEALTH STATUS QUESTIONNAIRE 2.0

The Health Status Questionnaire 2.0 (HSQ 2.0), an assessment from Pearson Assessments, is an outcomes measurement tool that yields a profile of scores on eight health attributes, an index of health status change, and an indication of risk for the presence of a depressive disorder. This instrument is designed to be easily administered via self-report, personal interview, or telephone interview. Designed as a general outcomes measure to be used in all settings that provide primary or mental health care services, it captures aspects of both physical and emotional health.

Abbreviated Name: HSQ
Author(s): David M. Radosevich
Purpose: To capture aspects of both physical and emotional health
Population: Adult / Adolescent
Age Range : +14 years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-/ Interviewer/ Telephone-administered
Time required:	5-10 minutes
Response Options:	Yes/No and Likert scale
Scoring:	Global score Scores by dimension
Score Direction:	Lower scores show better QoL

Number of Items: 39
Original Language: English
Existing Translations : French, Spanish

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Contact for information and permission to use:

NCS Assessments
NCS Pearson, Inc.
Phone: +1 800 627 7271
Fax: +1 800 632 9011
E-mail: assessment@ncs.com
Website: www.ncspearson.com

Dimensions covered by the questionnaire :

- Health Perception
- Physical Functioning
- Role Limitations/Physical Health
- Role Limitations/Emotional Problems
- Social Functioning
- Mental Health
- Bodily Pain
- Energy/Fatigue
- Physical functioning

Key References:

1. Radosevich DM, Wetzler H, Wilson SM. Health status questionnaire (HSQ) 2.0: scoring comparisons and reference data. Bloomington, Minn: Health Outcomes Institute, 1994.

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Todays Date is : ____ ____ /____ ____ /____ ____
month day year 104.49

Mode of Collection

Self-Administered 1
Personal Interview 2
Telephone Interview 3
Mail 4
Other 5

101.1

Administrative Use Only:

Patient ID_____

Physician ID_____

Clinic ID_____

0.0.0, 104.52, 104.53

Health Status Questionnaire 2.0

TO BE COMPLETED BY PATIENT

HSQ 2.0
Type Specification 04/01/93
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(Question 1-36 reprinted with permission of the RAND Corporation)

(11-08-94) 1

Health Status Questionnaire

TO BE COMPLETED BY PATIENT

INSTRUCTIONS:
This survey asks for your views about your health. This information will be summarized in your medical record and will help your doctors keep track of how you feel and how well you are able to do your usual activities.

Answer every question by circling the appropriate number, 1, 2, 3, ...If you are unsure about how to answer a question, please give the best answer you can and make a comment in the right margin.

1. In general, would you say your health is: *(circle one number)*

Excellent	1	
Very Good	2	
Good	3	
Fair	4	
Poor	5	100.1

2. Compared to one year ago, how would you rate your health in general **now**? *(circle one number)*

Much better now than one year ago	1	
Somewhat better now than one year ago	2	
About the same	3	
Somewhat worse now than one year ago	4	
Much worse now than one year ago	5	100.2

HEALTH AND DAILY ACTIVITIES

The following questions are about activities you might do during a typical day. Does **your health** limit you in these activities? If so, how much? *(circle one number on each line)*

	Yes, Limited a Lot	Yes, Limited a Little	No, Not Limited at All	
3. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3	
4. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3	
5. Lifting or carrying groceries	1	2	3	
6. Climbing several flights of stairs	1	2	3	
7. Climbing one flight of stairs	1	2	3	
8. Bending, kneeling, or stooping	1	2	3	
9. Walking more than a mile	1	2	3	
10. Walking several blocks	1	2	3	
11. Walking one block	1	2	3	
12. Bathing and dressing yourself	1	2	3	100.3

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**? *(circle one number on each line)*

	YES	NO	
13. Cut down on the amount of time you spent on work or other activities	1	2	
14. Accomplished less than you would like	1	2	
15. Were limited in the kind of work or other activities	1	2	
16. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2	100.4

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)? *(circle one number on each line)*

	YES	NO	
17. Cut down on the amount of time you spent on work or other activities	1	2	
18. Accomplished less than you would like	1	2	
19. Didn't do work or other activities as carefully as usual	1	2	100.5

20. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? *(circle one number)*

Not at all	1	
Slightly	2	
Moderately	3	
Quite a bit	4	
Extremely	5	100.6

PAIN

21. How much bodily pain have you had during the **past 4 weeks**? *(circle one number)* 100.7

None	1	
Very mild	2	
Mild	3	
Moderate	4	
Severe	5	
Very severe	6	

22. During the **past 4 weeks**, how much did pain interfere with your normal work (including work both outside the home and housework)? *(circle one number)*

Not at all	1	
A little bit	2	
Moderately	3	
Quite a bit	4	
Extremely	5	100.8

This is not full sample copy of HSQ 2.0 instrument.
Pearson Assessments do not allow HSQ 2.0 all test questions to be published in any situations.
All information about HSQ 2.0 you can also find on them webpage www.pearsonassessments.com

HEALTH UTILITIES INDEX

Health Utilities Index (HUI) is a family of generic health profiles and preference-based systems for the purposes of measuring health status, reporting health-related quality of life (HRQL), and producing utility scores. HRQL, as defined by Patrick and Erickson, "is the value assigned to duration of life as modified by the impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy". HUI questionnaires, designed to elicit responses from a wide variety of subjects, make it easy to incorporate such a patient-reported outcome (PRO) and utility instrument into a clinical study.

HUI evolved in response to the need for a standardized system to measure health status and HRQL to describe: 1) the experience of patients undergoing therapy; 2) long-term outcomes associated with disease or therapy; 3) the efficacy, effectiveness and efficiency of healthcare interventions; and 4) the health status of general populations.

HUI currently consists of two systems, HUI2 and HUI3, which together describe almost 1,000,000 unique health states. Each of HUI2 and HUI3 includes a generic comprehensive health status classification (i.e., profile) system and a generic HRQL utility scoring system. For most applications, HUI3 should be specified as the measure for primary analyses. It has the more detailed descriptive system of the two systems, full structural independence, and population norms available. HUI2 does offer distinct, independent attributes including self-care (for use with nursing home populations for example), emotion that focuses on worry/anxiety, and fertility. The two systems are independent but complementary, adding valuable information at low cost and with the HUI2 providing an efficient source of data for secondary/sensitivity analyses.

The HRQL scoring systems provide utility (preference) scores on a generic scale where dead = 0.00 and perfect health = 1.00. HUI scores meet or exceed the criteria for calculating quality-adjusted life years (QALY), and the requirements of published guidelines for economic evaluations of pharmaceutical and other health care services. The health status classification and HRQL scoring systems are generic in terms of applying to all people age 5 years and older in both clinical and general populations. A health-status classification system based on HUI2 and HUI3 suitable for children 3 to 5 years of age is under development.

HUI has been used in hundreds of clinical studies covering a wide variety of health problems and in numerous large general population surveys since 1990. There is a growing trend for the use of HUI as a primary health outcome measure in the form of QALYs.

HUI measures have strong theoretical foundations, are valid, are reliable, and are well accepted by patients and professionals.

HUI is a registered trademark of Health Utilities Inc., 88 Sydenham Street, Dundas, ON, L9H 2V3, Canada.

Abbreviated Name: HUI
Author(s): Furlong W, Feeny D, Torrance GW
Purpose: To describe health status, measure within-attribute morbidity and health-related quality of life, and produce utility scores
Population: All
Age Range : 5 to unlimited years, inclusive.
Type of Instrument: Utility, Disability/Physical Functioning, Economics, Quality of life
Mode of Administration:

Rater:	Self-/ Interviewer/ Telephone/ Caregiver- and Proxy-administered
Time required:	Self-administered versions: 6 to 10 minutes (mean= 8 minutes) Interviewer-administered versions: 3 to 6 minutes (mean= 4 minutes)
Response Options:	Yes/no -descriptive phrases of levels from HUI health status classification systems
Scoring:	Global score Scores by dimension
Score Direction:	Higher scores show better QoL
Weighting:	Yes

Number of Items:
Self-administered formats : 15-item multiple-choice questionnaires.
Interviewer-administered formats : 40-item skip-pattern questionnaires
Original Language: English
Existing Translations : French, Chinese (Simplified), Chinese (Traditional), Dutch, German, Italian, Portuguese, Spanish, Swedish, Japanese, Danish, Finnish, Czechoslovakian, Norwegian and Russian.

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Contact for information and permission to use:

William (Bill) Furlong
Health Utilities Inc.
88 Sydenham Street
Dundas ON L9H 2V3
Canada
Telephone: (905) 525-9140 extension 22389
FAX: (905) 627-7914

Dimensions covered by the questionnaire :

• **HUI 2:**
- Sensation (4 levels)
- Mobility (5 levels)
- Emotion (5 levels)
- Cognition (4 levels)
- Self-care (4 levels)
- Pain (5 levels)
- Fertility (3 levels)

• **HUI 3:**
- Vision (6 levels)
- Hearing (6 levels)
- Speech (5 levels)
- Ambulation (6 levels)
- Dexterity (6 levels)
- Emotion (5 levels)
- Cognition (6 levels)
- Pain (5 levels)

Key References:

1. Feeny D, Furlong W, Torrance GW et al. Multiattribute and single-attribute utility functions for the Health Utilities Index Mark 3 System. Medical Care 2002;40(2):113-128.

Background: The Health Utilities Index Mark 3 (HUI3) is a generic multiattribute preference-based measure of health status and health-related quality of life that is widely used as an outcome measure in clinical studies, in population health surveys, in the estimation of quality-adjusted life years, and in economic evaluations. HUI3 consists of eight attributes (or dimensions) of health status: vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain with 5 or 6 levels per attribute, varying from highly impaired to normal. Objectives: The objectives are to present a multiattribute utility function and eight single-attribute utility functions for the HUI3 system based on community preferences. Study Design: Two preference surveys were conducted. One, the modeling survey, collected preference scores for the estimation of the utility functions. The other, the direct survey, provided independent scores to assess the predictive validity of the utility functions. Measures: Preference measures included value scores obtained on the Feeling Thermometer and standard gamble utility scores obtained using the Chance Board. Respondents: A random sample of the general population (> or =16 years of age) in Hamilton, Ontario, Canada. Results: Estimates were obtained for eight single-attribute utility functions and an overall multiattribute utility function. The intraclass correlation coefficient between directly measured utility scores and scores generated by the multiattribute function for 73 health states was 0.88. Conclusions: The HUI3 scoring function has strong theoretical and empirical foundations. It performs well in predicting directly measured scores. The HUI3 system provides a practical way to obtain utility scores based on community preferences.

2. Furlong W, Feeny D, Torrance GW, Barr RD. The Health Utilities Index system for assessing health-related quality of life in clinical studies. Annals of Medicine 2001;33:375-384.

This paper reviews the Health Utilities Index (HUI) systems as means to describe health status and obtain utility scores reflecting health-related quality of life (HRQoL). The HUI Mark 2 (HUI2) and Mark 3 (HUI3) classification and scoring systems are described. The methods used to estimate multiattribute utility functions for HUI2 and HUI3 are reviewed. The use of HUI in clinical studies for a wide variety of conditions in a large number of countries is illustrated. HUI provides a comprehensive description of the health status of subjects in clinical studies. HUI has been shown to be a reliable, responsive and valid measure in a wide variety of clinical studies. Utility scores provide an overall assessment of the HRQoL of patients. Utility scores are also useful in cost-utility analyses and related studies. General population norm data are available. The widespread use of HUI facilitates the interpretation of results and permits comparisons. HUI is a useful tool for assessing health status and HRQoL in clinical studies.

3. Feeny DH, Furlong W, Boyle M, Torrance GW. Health Utilities Index. In : Spilker B, ed. Quality of Life and Pharmacoeconomics in Clinical Trials. 2nd Edition. Philadelphia : Lipponcott-Raven Press ; 1996 :85-95.
4. Torrance GW, Feeny DH, Furlong WJ et al. Multi-attribute preference functions for a comprehensive health status classification system : Health Utilities Index Mark 2. Medical Care 1996;34:702-722.

The Health Utilities Index Mark 2 (HUI:2) is a generic multiattribute, preference-based system for assessing health-related quality of life. Health Utilities Index Mark 2 consists of two components: a seven-attribute health status classification system and a scoring formula. The seven attributes are sensation, mobility, emotion, cognition, self-care, pain, and fertility. A random sample of general population parents were interviewed to determine cardinal preferences for the health states in the system. The health states were defined as lasting for a 60-year lifetime, starting at age 10. Values were measured using visual analogue scaling. Utilities were measured using a standard gamble technique. A scoring formula is provided, based on a multiplicative multiattribute utility function from the responses of 194 subjects. The utility scores are death-anchored (death = 0.0) and form an interval scale. Health Utilities Index Mark 2 and its utility scores can be useful to other researchers in a wide variety of settings who wish to document health status and assign preference scores.

5. Feeny D, Furlong W, Boyle M, Torrance GW. Multiattribute health status classification systems: Health Utilities Index.. Pharmacoeconomics 1995:7:490-502.

In this article, multi-attribute approaches to the assessment of health status are reviewed with a special focus on 2 recently developed systems, the Health Utilities Index (HUI) Mark II and Mark III systems. The Mark II system consists of 7 attributes: sensation, mobility, emotion, cognition, self-care, pain and fertility. The Mark III system contains 8 attributes: vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain. Each attribute consists of multiple levels of functioning. A combination of levels across the attributes constitutes a health state. The HUI systems are deliberately focused on the fundamental core attributes of health status, and on the capacity of individuals to function with respect to these attributes. Thus, the measure obtained constitutes a pure description of health status, uncontaminated by differential opportunity or preference. Multi-attribute systems provide a compact but comprehensive framework for describing health status for use in population health and programme evaluation studies. An important advantage of such systems is their ability to simultaneously provide detail on an attribute-by-attribute basis and to capture combinations of deficits among attributes. An additional advantage is their compatibility with multi-attribute preference functions, which provide a method for computing a summary health-related quality-of-life score for each health state.

6. Torrance GW, Furlong W, Feeny D et al. Multi-attribute preference functions : Health Utilities Index. Pharmacoeconomics 1995;7:503-520.

Multi-attribute utility theory, an extension of conventional utility theory, can be applied to model preference scores for health states defined by multi-attribute health status classification systems. The type of preference independence among the attributes determines the type of preference function required: additive, multiplicative or multilinear. In addition, the type of measurement instrument used determines the type of preference score obtained: value or utility. Multi-attribute utility theory has been applied to 2 recently developed multi-attribute health status classification systems, the Health Utilities Index (HUI) Mark II and Mark III systems. Results are presented for the Mark II system, and ongoing research is described for the Mark III system. The theory is also discussed in the context of other well known multi-attribute systems. The HUI system is an efficient method of determining a general public-based utility score for a specified health outcome or for the health status of an individual. In clinical populations, the scores can be used to provide a single summary measure of health-related quality of life. In cost-utility analyses, the scores can be used as quality weights for calculating quality-adjusted life years. In general populations, the measure can be used as quality weights for determining population health expectancy.

7. David Feeny, William Furlong and George W. Torrance. The Health Utilities Index: An Update. Quality of Life Newsletter 1999;22:8-9

As many readers of Quality of Life Newsletter know the Health Utilities Index (HUI) is a family of generic health status and health-related quality of life (HRQL) measures. The family of measures includes the Health Utilities Index Mark 1 (HUI1), Mark 2 (HUI2), and Mark 3 (HUI3) systems. Each HUI measure includes a health-status classification system and a preference-based scoring formula. Although HUI1 is still used, HUI2 and HUI3 are much more frequently used both in clinical and population health studies and will be the focus of this note.

HUI2 Multi-Attribute Health Status Classification System
(From Torrance et al. Medical Care 1996, Table 1, page 706)

Attribute: Level	Description [a]
Sensation:	
1	Able to see, hear and speak normally for age.
2	Requires equipment to see or hear or speak.
3	Sees, hears, or speaks with limitations even with equipment.
4	Blind, deaf or mute.
Mobility:	
1	Able to walk, bend, lift, jump, and run normally for age.
2	Walks, bends, lifts, jumps, or runs with some limitations but does not require help.
3	Requires mechanical equipment (such as canes, crutches, braces or wheelchair) to walk or get around independently.
4	Requires the help of another person to walk or get around and requires mechanical equipment as well.
5	Unable to control or use arms and legs.
Emotion:	
1	Generally happy and free from worry.
2	Occasionally fretful, angry, irritable, anxious, depressed, or suffering “night terrors”.
3	Often fretful, angry, irritable, anxious, depressed, or suffering “night terrors”.
4	Almost always fretful, angry, irritable, anxious, depressed.
5	Extremely fretful, angry, irritable, anxious or depressed usually requiring hospitalisation or psychiatric institutional care.
Cognition:	
1	Learns and remembers school work normally for age.
2	Learns and remembers school work more slowly than classmates as judged by parents and/or teachers.
3	Learns and remembers very slowly and usually requires special educational assistance.
4	Unable to learn and remember.
Self-Care:	
1	Eats, bathes, dresses, and uses the toilet normally for age.
2	Eats, bathes, dresses, or uses the toilet independently with difficulty.
3	Requires mechanical equipment to eat, bathe, dress, or use the toilet independently.
4	Requires the help of another person to eat, bathe, dress, or use the toilet.

Pain:

1 Free of pain and discomfort.
2 Occasional pain. Discomfort relieved by non-prescription drugs or self-control activity without disruption of normal activities.
3 Frequent pain. Discomfort relieved by oral medicines with occasional disruption of normal activities.
4 Frequent pain; frequent disruption of normal activities. Discomfort requires prescription narcotics for relief.
5 Severe pain. Pain not relieved by drugs and constantly disrupts normal activities.

Fertility:

1 Able to have children with a fertile spouse.
2 Difficulty in having children with a fertile spouse.
3 Unable to have children with a fertile spouse.

[a] Level descriptions are worded here exactly as presented to respondents in HUI2 preference survey.

HUI3 Multi-Attribute Health Status Classification System
(from Feeny et al. PharmacoEconomics 1995;7(6), Table III, page 494)

Attribute:
Level. Description

Vision:

1. Able to see well enough to read ordinary newsprint and recognize a friend on the other side of the street, without glasses or contact lenses.
2. Able to see well enough to read ordinary newsprint and recognize a friend on the other side of the street, but with glasses or contact lenses.
3. Able to read ordinary newsprint with or without glasses but unable to recognize a friend on the other side of the street, even with glasses or contact lenses.
4. Able to recognize a friend on the other side of the street with or without glasses but unable to read ordinary newsprint, even with glasses or contact lenses.
5. Unable to read ordinary newsprint and unable to recognize a friend on the other side of the street, even with glasses or contact lenses.
6. Unable to see at all.

Hearing:

1. Able to hear what is said in a group conversation with at least three other people, without a hearing aid.
2. Able to hear what is said in a conversation with one other person in a quiet room without a hearing aid, but requires a hearing aid to hear what is said in a group conversation with at least three other people.
3. Able to hear what is said in a conversation with one other person in a quiet room with a hearing aid, and able to hear what is said in a group conversation with at least three other people with a hearing aid.
4. Able to hear what is said in a conversation with one other person in a quiet room without a hearing aid, but unable to hear what is said in a group conversation with at least three other people even with a hearing aid.
5. Able to hear what is said in a conversation with one other person in a quiet room with a hearing aid, but unable to hear what is said in a group conversation with at least three other people even with a hearing aid.
6. Unable to hear at all.

Speech:

1. Able to be understood completely when speaking with strangers or people who know me well.
2. Able to be understood partially when speaking with strangers but able to be understood completely when speaking with people who know me well.
3. Able to be understood partially when speaking with strangers or people who know me well.
4. Unable to be understood when speaking with strangers but able to be understood partially by people who know me well.
5. Unable to be understood when speaking to other people (or unable to speak at all).

Ambulation:

1. Able to walk around the neighbourhood without difficulty, and without walking equipment.
2. Able to walk around the neighbourhood with difficulty; but does not require walking equipment or the help of another person.
3. Able to walk around the neighbourhood with walking equipment, but without the help of another person.
4. Able to walk only short distances with walking equipment, and requires a wheelchair to get around the neighbourhood.
5. Unable to walk alone, even with walking equipment. Able to walk short distances with the help of another person, and requires a wheelchair to get around the neighbourhood.
6. Cannot walk at all.

Dexterity:

1. Full use of two hands and ten fingers.
2. Limitations in the use of hands or fingers, but does not require special tools or help of another person.
3. Limitations in the use of hands or fingers, is independent with use of special tools (does not require the help of another person).
4. Limitations in the use of hands or fingers, requires the help of another person for some tasks (not independent even with use of special tools).
5. Limitations in use of hands or fingers, requires the help of another person for most tasks (not independent even with use of special tools).
6. Limitations in use of hands or fingers, requires the help of another person for all tasks (not independent even with use of special tools).

Emotion:

1. Happy and interested in life.
2. Somewhat happy.
3. Somewhat unhappy.
4. Very unhappy.
5. So unhappy that life is not worthwhile.

Cognition:

1. Able to remember most things, think clearly and solve day to day problems.
2. Able to remember most things, but has a little difficulty when trying to think and solve day to day problems.
3. Somewhat forgetful, but able to think clearly and solve day to day problems.
4. Somewhat forgetful, and has a little difficulty when trying to think or solve day to day problems.
5. Very forgetful, and has great difficulty when trying to think or solve day to day problems.
6. Unable to remember anything at all, and unable to think or solve day to day problems.

Pain:

1. Free of pain and discomfort.
2. Mild to moderate pain that prevents no activities.
3. Moderate pain that prevents a few activities.
4. Moderate to severe pain that prevents some activities.
5. Severe pain that prevents most activities.

ILLNESS BEHAVIOR QUESTIONNAIRE

Illness Behavior Questionnaire (IBQ) includes seven scales that evaluate abnormal illness behavior, which Pilowsky defined as "the persistence of an inappropriate or maladaptive mode of perceiving, evaluating or acting in relation to one's own state of health despite the fact that a doctor has provided a lucid and accurate appraisal of the situation and management to be followed."

The seven scales of the Illness Behavior Questionnaire are: 1) the general hypochondriasis scale, which assesses the extent of fearful attitudes toward illness that include some insight into the excessive nature of the fear; 2) the disease conviction scale, which measures the strength of the belief that a somatic disorder is present and the degree of reluctance to accept reassurance (questions focused on bodily symptoms and sensations and sleep disturbances); 3) the psychological versus somatic focusing scale, which measures the extent of a psychological versus a somatic focus in perception of the disease (high scores indicate possible adoption of a psychological perspective on the illness; low scores reflect a focus on somatic problems and a tendency to reject the possibility of a psychological dimension to the condition); 4) the affective inhibition scale, on which high scores indicate the inability to communicate feelings, especially negative ones; 5) the affective disturbance scale, which assesses the presence of anxiety, depression, and tension; 6) the denial scale, which measures the tendency to deny life stresses and to attribute all current difficulties to a somatic disorder (high scores indicate a belief that a cure for physical problems would solve all life problems; low scores indicate a belief that ongoing life problems would continue even if the person was physically well); and 7) the irritability scale, on which high scores indicate the presence of interpersonal friction.

Abbreviated Name: IBQ
Author(s): Issy Pilowsky, Neil Spence
Purpose: To assess patient's attitudes, ideas, affects, and attributions in relation to illness
Population: Adult
Age Range : 18+ years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-administered
Time required:	15 minutes
Response Options:	Yes/No
Scoring:	Scores by dimension - Whiteley Index of Hypochondriasis Score - Affective State Score - Disease Affirmation Score
Score Direction:	Depending on the score / dimension considered

Number of Items: 62
Original Language: English
Existing Translations: Chinese, Dutch, Finnish, German, Greek, Hindi, Italian, Japanese, Norwegian, Polish, Serbo-Croatian, Spanish, Swedish

Contact for information and permission to use:

Professor Issy Pilowsky
Visiting Professor
Department of Psychological Medicine
University of Sydney
Camperdown New South Wales 2006, Australia
Phone:02 98100970
Fax: 9810-1897
E-mail: issyp@med.usyd.edu.au

Dimensions covered by the questionnaire :

- General (phobic) Hypochondriasis
- Disease conviction
- Psychological vs. somatic focussing
- Affective inhibition
- Affective disturbance
- Denial
- Irritability

Key References:

1. Pilowsky I, Spence N, Cobb J, Katsikitis M. The Illness Behavior Questionnaire as an aid to clinical assessment. Gen Hosp Psychiatry. 1984 Apr;6(2):123-30.

The Illness Behavior Questionnaire (IBQ) is a 62-item self-report instrument that provides information relevant to the delineation of a patient's attitudes, ideas, affects, and attributions in relation to illness. The scores generated are described, and nine clinical vignettes are presented, together with IBQ score profiles and interpretations to illustrate the manner in which the latter may complement other clinical data. The ways in which individuals react to their own health status is becoming of greater importance as the taking of responsibility for one's own health is increasingly emphasized. The IBQ provides information that should be relevant to the management of patients, regardless of the specific nature of their illness.

2. Pilowsky I, Chapman CR, Bonica JJ. Pain, depression, and illness behavior in a pain clinic population. Pain. 1977 Dec;4(2):183-92.

The relationship between depression, illness behavior and persistent pain was studied in 100 patients referred to the University of Washington Hospital Pain Clinic. The instruments used were the Illness Behavior Questionnaire (IBQ) and the Levine-Pilowsky Depression Questionnaire (LPD). To delineate those aspects of illness behavior characteristic of the Pain Clinic group, their scores were compared to those attained on the IBQ by a Family Medicine Clinic sample. The Pain Clinic group showed greater conviction of disease and somatic preoccupation than the comparison group. Further, they were reluctant to consider their health problems in psychologic terms, and denied current life problems. The Pain Clinic group's performance on the LPD indicated a low degree of depressive affect overall and few patients manifesting a depressive syndrome. The association between IBQ and depression scores suggests that the predominant clinical pattern presented by pain clinic patients is best characterized as a form of "abnormal illness behavior".

3. Pilowsky I, Spence N. Illness behaviour syndromes associated with intractable pain. Pain. 1976; 2:67-71

One hundred patients, referred for the management of intractable pain, completed a 52-item Illness Behaviour Questionnaire (IBQ). Responses were scored on 7 scales: general hypochondriasis, disease conviction, psychological versus somatic perception of illness, affective inhibition, affective disturbance, denial, and irritability. IBQ scale profiles were subjected to numerical analysis and 6 taxonomic clusters were identified. Patients in groups 1-3 were characterized by a relatively non-neurotic, reality-oriented attitude to illness, as indicated by low scores on the first three scales. Patients in groups 4-6 manifested greater evidence of 'abnormal illness behaviour', and presented syndromes resembling 'hysteria', 'conversion reaction', and 'hypothchondriasis' respectively.

4. Pilowsky I. "Abnormal Illness Behaviour" (1997);Wiley and Son:Chichester ISBN: 0-471-96573-1

NAME:_____**U.R. NO:**_____
(Surname) **(Given names)**

DATE:_____ **AGE:**_____ **LENGTH OF ILLNESS:** _____

HEALTH SURVEY

On the following pages you will find a number of questions about your health and how it affects you. For the purposes of our survey it is important that you complete **every** question even though some of them may not be directly applicable to you.

We thank you very much for your co-operation.

„: I. Pilowsky and N.D. Spence. Inquiries: Dept. of Psychiatry, University of Adelaide, South Australia

I.B.Q.

Here are some questions about you and your illness. Circle either YES or NO to indicate your answer to each question.

1.	Do you worry a lot about your health?	YES NO
2.	Do you think there is something seriously wrong with your body?	YES NO
3.	Does your illness interfere with your life a great deal?	YES NO
4.	Are you easy to get on with when you are ill?	YES NO
5.	Does your family have a history of illness?	YES NO
6.	Do you think you are more liable to illness than other people?	YES NO
7.	If the doctor told you that he could find nothing wrong with you would you believe him?	YES NO
8.	Is it easy for you to forget about yourself and think about all sorts of other things?	YES NO
9.	If you feel ill and someone tells you that you are looking better, do you become annoyed?	YES NO
10.	Do you find that you are often aware of various things happening in your body?	YES NO
11.	Do you ever think of your illness as a punishment for something you have done wrong in the past?	YES NO
12.	Do you have trouble with your nerves?	YES NO
13.	If you feel ill or worried, can you be easily cheered up by the doctor?	YES NO
14.	Do you think that other people realise what its like to be sick?	YES NO
15.	Does it upset you to talk to the doctor about your illness?	YES NO
16.	Are you bothered by many pains and aches?	YES NO
17.	Does your illness affect the way you get on with your family or friends a great deal?	YES NO
18.	Do you find that you get anxious easily?	YES NO
19.	Do you know anybody who has had the same illness as you?	YES NO
20.	Are you more sensitive to pain than other people?	YES NO
21.	Are you afraid of illness?	YES NO
22.	Can you express your personal feelings easily to other people?	YES NO
23.	Do people feel sorry for you when you are ill?	YES NO
24.	Do you think that you worry about your health more than most people	YES NO
25.	Do you find that your illness affects your sexual relations?	YES NO
26.	Do you experience a lot of pain with your illness?	YES NO
27.	Except for your illness, do you have any problems in your life?	YES NO
28.	Do you care whether or not people realise you are sick?	YES NO
29.	Do you find that you get jealous of other people's good health?	YES NO
30.	Do you ever have silly thoughts about your health which you can't get out of your mind, no matter how hard you try?	YES NO

31.	Do you have any financial problems?	YES NO
32.	Are you upset by the way people take your illness?	YES NO
33.	Is it hard for you to believe the doctor when he tells you there is nothing for you to worry about?	YES NO
34.	Do you often worry about the possibility that you have got a serious illness?	YES NO
35.	Are you sleeping well?	YES NO
36.	When you are angry, do you tend to bottle up your feelings?	YES NO
37.	Do you often think that you might suddenly fall ill?	YES NO
38.	If a disease is brought to your attention (through the radio, television, newspapers or someone you know) do you worry about getting it yourself?	YES NO
39.	Do you get the feeling that people are not taking your illness seriously enough?	YES NO
40.	Are you upset by the appearance of your face or body?	YES NO
41.	Do you find that you are bothered by many different symptoms?	YES NO
42.	Do you frequently try to explain to others how you are feeling?	YES NO
43.	Do you have any family problems?	YES NO
44.	Do you think there is something the matter with your mind?	YES NO
45.	Are you eating well?	YES NO
46.	Is your bad health the biggest difficulty of your life?	YES NO
47.	Do you find that you get sad easily?	YES NO
48.	Do you or fuss over small details that seem unimportant to others?	YES NO
49.	Are you always a co-operative patient?	YES NO
50.	Do you often have the symptoms of a very serious disease?	YES NO
51.	Do you find that you get angry easily?	YES NO
52.	Do you have any work problems?	YES NO
53.	Do you prefer to keep your feelings to yourself?	YES NO
54.	Do you often find that you get depressed?	YES NO
55.	Would all your worries be over if you were physically healthy?	YES NO
56.	Are you more irritable towards other people?	YES NO
57.	Do you think that your symptoms may be caused by worry?	YES NO
58.	Is it easy for you to let people know when you are cross with them?	YES NO
59.	Is it hard for you to relax?	YES NO
60.	Do you have personal worries which are not caused by physical illness?	YES NO
61.	Do you often find that you lose patience with other people?	YES NO
62.	Is it hard for you to show people your personal feelings?	YES NO

INDEX FOR MEASURING HEALTH

Index for Measuring Health was developed in 1970 to provide the basis for a universal measure of health. It uses a ten point scale to weight a patient's health.

Abbreviated Name: Grogono Health Index
Author(s): Alan W. Grogono and D.J. Woodgate
Purpose: To measure health and to assess severity of disease and allow severity of disease, efficacy of treatment, and cost
Population: All ages
Type of Instrument: Utility/Quality of life
Mode of Administration:

Rater:	Proxy-administered
Time required:	2 minutes
Response Options:	Likert scale
Scoring:	Scores by items
Score Direction:	Higher scores show better QoL

Number of Items: 10
Original Language: English

Copyright: Lancet 1971

Contact for information and permission to use:

Alan W. Grogono
Tel: (1) 843-842-5926
Fax: (1) 843-842-5936
Email: grog@grogono.com

Dimensions covered by the questionnaire :

- Work
- Recreation
- Physical suffering
- Mental suffering
- Communication
- Sleep
- Dependency on others
- Feeding
- Excretion
- Sexual activity

Key References:

1. Grogono AW, Woodgate DJ. Index for measuring health. Lancet 1971; 2(7732):1024-6.

A health index is described which expresses health numerically between 0 and 1. Each patient scores 0, 1/2, or 1 for each of ten "questions" relating to well-being, the index being the total score divided by 10. Twenty seven patients were assessed by more than one observer, and good agreement between scores was obtained. It is suggested that the index could be used to allot priorities in treatment and research and to apply cost-benefit techniques to health.

INDEX FOR MEASURING HEALTH

A.W.GROGONO
Department of Anaesthesia, Royal Free Hospital
London NW3 2XJ

D.J. WOODGATE
St. Andrew's Hospital, Billericay, Essex

Summary:

A health index is described which expresses health numerically between 0 and 1. Each patient scores 0, 1/2, or 1 for each of ten "questions" relating to well-being, the index being the total score divided by 10. Twenty seven patients were assessed by more than one observer, and good agreement between scores was obtained. It is suggested that the index could be used to allot priorities in treatment and research and to apply cost-benefit techniques to health.

INTRODUCTION

Medicine- the study, prevention, and treatment of ill-health – is one of the largest industries there is. In 1968 – 69, the United Kingdom spent 4.69% of her gross national product on health care, while the United States spent 6.71%.[1] Despite the size of this industry we have as yet no rational basis upon which to organise and distribute our resources. This must in part be attributed to the absence of any method of measuring efficacy: we have no method of measuring a patient's health before and after treatment. If we had, we might be able to allocate limited treatment resources to areas where they would be most beneficial and research to areas where it is most required, and we could also apply cost-effectiveness calculations to much medical work.

This paper reports the development and assessment of a health index which measures health and allows severity of disease, efficacy of treatment, and cost to be compared.

DEVELOPMENT

Medical care includes frequent evaluation of the patient's health, but the measurement is practical or relative and is expressed in such terms as "fit for light duty" or "better than yesterday". Such assessments serve the patient and his doctor fairly well but they do not lend themselves to numerical representation. Indeed, such representation is impossible without first having a suitable definition of health upon which to base the score. The World Health Organisation 2 defines health as a state of physical, mental, and social well-being, and this definition was used as a basis for some early trials. However, it soon became apparent that although it was a reasonable definition, it did not encourage precise scoring. What one observer considered "mental" another considered 'social", and what one observer felt was minor social ill-health was major to another.

After this experience, we examined the activities and aspects which together comprise the pattern of daily life; many of these appeared to overlap or encompass each other, and a cumbersome and inefficient method of scoring would have been the result. However, by elimination of some items, and grouping of others, the list was reduced to ten which were comprehensive but without obvious redundancy:

(1) Work
(2) Recreation
(3) Physical suffering
(4) Mental suffering
(5) Communication
(6) Sleep
(7) Dependency on others
(8) Feeding
(9) Excretion
(10) Sexual activity

These ten factors were used as the basis for scoring a patient's health, each factor being considered in the same way: "Is there any impairment due to the patient's ill-health?". This approach corresponds to a definition of health as: "No impairment in the ten aspects of life listed." Although not an elegant definition, it seemed likely to lend itself to unambiguous scoring.

The scoring system selected was to allocate for each factor 1, 1/2, or 0, according to whether the patient was normal, impaired, or incapacitated. The total was then divided by ten to yield the health index. The score for a normal person was thus 1, ill health causing a reduced score and extreme ill-health scoring 0. This method of scoring health was evaluated.

ASSESSMENT

The ten questions were printed as a list (see figure), with space for recording details of patient and observer, and room for several scores to be made. The interviewer was provided with instructions (see legend to figure) on the interpretation and scoring of some of the questions.

Twenty observers made 180 assessments on twenty seven patients. The observers included consultants, registrars, housmen, and students, and the patients were volunteers with a variety of complaints who were chosen when an opportunity presented for several observers to see the patient.

The scores were made quickly and easily, much of the information being already obtained from a normal consultation. The scores in this series ranged from 0.25 scored by a man with severe asthma to 1.0 scored by a man awaiting admission for excision of a tongue papilloma.

There is no accepted alternative measurement against which the accuracy of the scoring system can be gauged, but when the patients were ranked according to score, there did not seem to be any striking anomalies (see table).

The variation between observers was slight, with scores usually differing by no more than 0.05. This reproducibility was assessed in this series in the following way. All the scores obtained on any patient at one session were paired in an arrangement based on the alphabetical order of the names of the observers, any unpaired score being discarded. This yielded 72 pairs of observations for which the correlation coefficient was 0.883, with a standard error of 0.118.

Many patients were seen more than once. For example, a woman with asthma was treated for five days; one observer judged her score to have risen from 0.4 to 0.55, compared to 0.45 to 0.70 for a second observer. In such cases the change in score was calculated and comparison was again made on an arrangement based on the alphabetical order of observers, any unpaired score being discarded. This yielded 25 pairs of observations. On all but one occasion the observers agreed on the direction of change, and there was good agreement on the magnitude of the change. The correlation coefficient was 0.884 with a standard error of 0.196.

DISCUSSION

The development of this health index was stimulated by consideration of the statistics in current use. For example, the mean bed occupancy has been widely used in the United Kingdom. This provides a very inadequate representation of efficiency and tends to encourage such practices as keeping a patient in hospital until the next operating-list. To run a factory on "mean warehouse occupancy" would be commercial suicide, for it would encourage overcrowding, stagnation, and buildings of inadequate size.

Other measurements, although useful, have only limited applicability. For example, the benefit of influenza vaccination may be inferred from the percentage of factory staff off work. However, to extend this measurement to the general assessment of health services would be inappropriate; apparent "efficiency" might result from various measures ranging from fining absentees to compulsory sterilisation of the female labour force. A satisfactory measure of efficiency must be applicable to a wide range of problems and should produce no anomalies in the society in which it is to be used.

The health index described here may be used as a weighting factor giving a value in health terms to any period of time. The product is conveniently expressed in "health years". Thus, one year in full health is one health-year, one year with a health index of 0.5 is 1/2 health year, one month at full health is 1/12 health-year, and one month with a health index of 0.5 is 1/24 health year. Benefit from medical treatment can thus be expressed as health years or parts of a health year gained to the patient as a result of the measures under consideration. In the same way the impact of a disease can be

expressed as health-years lost to an individual or to the community. Such knowledge could be used in allocating resources available for treatment and research.
If the health index is combined with satisfactory measurements of cost it should be possible to apply cost-benefit analysis to health. Hitherto the appropriate information about cost has not been available, but the massive collection of data now being undertaken in the Hospital Activity Analysis project could provide a basis for satisfactory costing.

Table: DIAGNOSES OF PATIENTS PLACED IN RANK ORDER ACCORDING TO HEALTH INDEX SCORED.

Score	Diagnosis
1.00	Benign Tongue Papilloma
0.95	Varicose veins Vaginal prolapse Vulval warts
0.90	Controlled diabetes Varicose veins Infertility for investigation
0.85	- -
0.80	- -
0.75	Fistula-in-ano Pregnancy for termination
0.70	Hernia Carpal tunnel syndrome Hodgkin's disease
0.65	Carcinoma of stomach Myocardial infarction Lumbar pain for investigation
0.60	- -
0.55	Hiatus hernia
0.50	- -
0.45	Gout in a patient with coarctation and alcoholic neuropathy Diabetic neuropathy
0.40	- -
0.35	Heart failure
0.30	Acute cholecystitis
0.25	Status asthmaticus

HEALTH INDEX SCORE SHEET

Date:		Observer:

Patient:	Age:	Sex:	Hosp. No.

Diagnosis:

	Score 1, 1/2 or 0 (i.e normal scores 1)							
Date								
1. Work: Normal, impaired or reduced, prevented								
2. Hobbies and recreation: Normal, impaired or reduced, prevented								
3. Is patient free from malaise, pain or suffering?								
4. Is patient free from worry or unhappiness?								
5. Does patient communicate satisfactorily?								
6. Does patient sleep satisfactorily?								
7. Is patient independent of others for acts of daily living (.e.g washing, feeding, dressing, moving)?								
8. Does patient eat and enjoy his food?								
9. Is micturition and defaecation normal?								
10. Has patient's state of health altered his sex life?								
Total (÷ 10)								

Notes and comments:

Health index record form

The following notes apply to individual questions:

(1) Medical advice leading to light duty or absence from work (e.g., hospitalization) will result in a score of 1/2 or 0, even if the patient feels he has a greater capacity. Someone able to work while in hospital (e.g., an author) may score normally. When retirement is compulsory due to age, the maximum score is still 1. This score is to be awarded on the basis of ability to do tasks associated with everyday life.

(5) Language barrier alone should not produce a reduced score.

(7) The score should be reduced when the assistance of others is required on medical grounds or on medical advice.

(8) Patients on a diet may have a reduced score if they dislike it.

(9) If there is a *major* abnormality of either micturition or defaecation the appropriate score is 0.

(10) Infants, children, and the celibate would normally score 1 on the basis that their behaviour is regarded as normal and not as requiring therapy. In these groups this score will normally remain as 1 even during disease, since no deprivation occurs. However, enforced celibacy (e.g., hospitalization) which causes a feeling of deprivation may result in a reduced score.

I feel tense or 'wound up':	**A**	**I feel as if I am slowed down:**	**D**
Most of the time	3	Nearly all of the time	3
A lot of the time	2	Very often	2
Time to time, occasionally	1	Sometimes	1
Not at all	0	Not at all	0
I still enjoy the things I used to enjoy:	**D**	**I get a sort of frightened feeling like 'butterflies in the stomach':**	**A**
Definitely as much	0	Not at all	0
Not quite so much	1	Occasionally	1
Only a little	2	Quite often	2
Not at all	3	Very often	3
I get a sort of frightened feeling like something awful is about to happen:	**A**	**I have lost interest in my appearance:**	**D**
Very definitely and quite badly	3	Definitely	3
Yes, but not too badly	2	I don't take as much care as I should	2
A little, but it doesn't worry me	1	I may not take quite as much care	1
Not at all	0	I take just as much care as ever	0
I can laugh and see the funny side of things:	**D**	**I feel restless as if I have to be on the move:**	**A**
As much as I always could	0	Very much indeed	3
Not quite so much now	1	Quite a lot	2
Definitely not so much now	2	Not very much	1
Not al all	3	Not at all	0
Worrying thoughts go through my mind:	**A**	**I look forward with enjoyment to things:**	**D**
A great deal of the time	3	A much as I ever did	0
A lot of the time	2	Rather less than I used to	1
From time to time but not too often	1	Definitely less than I used to	3
Only occasionally	0	Hardly at all	2
I feel cheerful:	**D**	**I get sudden feelings of panic:**	**A**
Not at all	3	Very often indeed	3
Not often	2	Quite often	2
Sometimes	1	Not very often	1
Most of the time	0	Not at all	0
I can sit at ease and feel relaxed:	**A**	**I can enjoy a good book or radio or TV programme:**	**D**
Definitely	0	Often	0
Usually	1	Sometimes	1
Not often	2	Not often	2
Not at all	3	Very seldom	3

KIDSCREEN

The KIDSCREEN instruments are a family of generic quality of life measures that have been designed and normed for children and adolescent aged between 8 to 18 years. It was developed simultaneously in several European countries taking children's concepts of health and well-being into consideration. KIDSCREEN can be used as a screening, monitoring and evaluation tool in representative national and European health surveys.

Three KIDSCREEN instruments are available in child and adolescent as well as parent / proxy versions: KIDSCREEN-52 (long version) covering ten HRQoL dimensions, KIDSCREEN-27 (short version) covering five HRQoL dimensions and the KIDSCREEN-10 Index as a global HRQoL score. Scores can be calculated for each dimension. T-values and percentages will be available for several countries stratified by age and gender.

The KIDSCREEN project was funded by the European Commission (grant number QLG-CT-2000- 00751 within the EC 5th Framework-Programme "Quality of Life and Management of Living Resources"). The KIDSCREEN project co-operates with the DISABKIDS project, which was also funded by the European Commission.

Abbreviated Name: KIDSCREEN-52 / KIDSCREEN-27 / KIDSCREEN-10 Index
Author(s): Ulrike Ravens-Sieberer, Angela Gosch, Luis Rajmil, Jeanet Bruil, Mick Power, Wolfgang Duer, Pascal Auquier, Thomas Abel, Ladislav Czemy, Joanna Mazur, Agnes Czimbalmos, Yannis Tountas, Curt Hagquist, Jean Kilroe, Michael Erhart, and the European KIDSCREEN Group
Purpose: Designed to obtain a self-report and an external assessment of health-related quality of life in children and adolescents in a wide range of ages and independently of current health status
Population: Adolescent / Pediatrics
Age Range : 8-18 years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-/ Proxy-administered
Time required:	KIDSCREEN-52 20-30 min/ KIDSCREEN-27 10-15 min/ KIDSCREEN-10 3-5 min
Response Options:	Likert scale
Scoring:	Scores by dimension/ KIDSCREEN-10 unidimensional
Score Direction:	Higher scores show better QoL

Number of Items:
KIDSCREEN-52: 52 items covering 10 HRQoL dimensions
KIDSCREEN-27: 27 items covering 5 HRQoL dimensions
KIDSCREEN-10 Index: 10 items general HRQoL Index.
Original Language: Czech, Dutch, English, French, German, Greek, Polish, Spanish, Swedish
Existing Translations : Korean, Portuguese

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Contact for information and permission to use:

Dr.Ulrike Ravens-Sieberer MPH
for the KIDSCREEN Group
Robert Koch Institute
Research Unit Psychosocial Health
Seestr. 10
13353 Berlin
Germany
Tel.: +49-30-4547-3436
Fax: +49-30-4547-3531
E-mail: Ravens-SiebererU@rki.de

Dimensions covered by the questionnaire :

KIDSCREEN-52

- Physical Well-being (5 items)
- Psychological Well-being (6 items)
- Moods and Emotions (7 items)
- Self-Perception (5 items)
- Autonomy (5 items)
- Parent Relations and Home Life (6 items)
- Social Support and Peers (6 items)
- School Environment (6 items)
- Social Acceptance (Bullying) (3 items)
- Financial Resources (3 items)

KIDSCREEN-27

- Physical Well-Being (5 items)
- Psychological Well- Being (7 items)
- Autonomy & Parents (7 items)
- Peers & Social Support (4 items)
- School Environment (4 items)

Key References:

1. Aymerich, M., Berra, S., Guillamón, I., Herdman, M., Alonso, J., Ravens-Sieberer, U. & Rajmil, L. (2005). Desarrollo de la versión en español del KIDSCREEN, un cuestionario de calidad de vida para la población infantil y adolescente. [Development of the Spanish version of the KIDSCREEN, a health-related quality of life instrument for children and adolescents.]. Gaceta Sanitaria, 19 (2), 93-102.

Aims: To describe the cross-cultural development and psychometric properties of the Spanish version of the KIDSCREEN questionnaire, a health related quality of life instrument (HRQL) for use in children and adolescents aged 8-18 years old. The questionnaire was cross-culturally developed in 13 European countries. Methods: A literature review and Delphi study were performed, allowing consensus to be reached on the instrument's contents and structure. More specific items and dimensions were generated in focus groups. Forward and back translation and cultural adaptation were carried out, together with a pre-test (cognitive debriefing) to select items that were acceptable in all the countries involved. A pilot study was performed to obtain the definitive version of the KIDSCREEN through Rasch analysis and preliminary information on the questionnaire's psychometric properties. Results: The focus groups generated 1642 possible items, which were reduced during the stages of translation-adaptation and pilot study. The definitive version of the questionnaire contains 52 items and 10 dimensions. In the Spanish version, there was less than 5% nonequivalence (acceptability) in any of the dimensions, floor and ceiling effects were acceptable, and all dimensions had Cronbach's alpha values of > 0.70 (internal consistency). Conclusions: The KIDSCREEN is the first HRQL instrument for children and adolescents to be developed simultaneously in several countries. The preliminary psychometric properties of the Spanish version were acceptable.

2. Bisegger, C., Cloetta, B., von Rueden, U., Abel, T., Ravens-Sieberer, U., and the European KIDSCREEN group. (2005). Health-related quality of life: gender differences in childhood and adolescence, Soz.-Präventivmed, 50, 281–291.

Objectives: To assess whether gender and age differences can be found in different aspects of health-related quality of life (HRQOL) of children and adolescents, and to what extent these results correspond to theoretical and empirical findings from developmental psychology. Methods: A newly developed HRQOL questionnaire was completed by 3,710 youths aged nine to 17 years in seven European countries. The "Kidscreen 52" questionnaire consists of 10 scales operationalising aspects of the physical, psychological and social dimensions of HRQOL. With the use of ANOVA and effect sizes, the influence of age and gender on aspects of HRQOL is reported. Results: Children report a very good quality of life largely independent of gender. After 12 years, HRQOL decreases in the majority of aspects. In the physical and psychological dimensions, a stronger decrease is found for females than for males. Conclusions: Children have higher HRQOL than adolescents in many aspects. With increasing age, HRQOL is frequently worse for females than for males. Examination of the individual aspects leads to a differentiation of the results with relevance for public health.

3. Colver A; SPARCLE Group. (2006). Study protocol: SPARCLE--a multi-centre European study of the relationship of environment to participation and quality of life in children with cerebral palsy. BMC Public Health. Apr 25;6:105.

Background: SPARCLE is a nine-centre European epidemiological research study examining the relationship of participation and quality of life to impairment and environment (physical, social and attitudinal) in 8-12 year old children with cerebral palsy. Concepts are adopted from the International Classification of Functioning, Disability and Health which bridges the medical and social models of disability. Methods/Design: A cross sectional study of children with cerebral palsy sampled from total population databases in 9 European regions. Children were visited by research associates in each country who had been trained together. The main instruments used were KIDSCREEN, Life-H, Strength and Difficulties Questionnaire, Parenting Stress Index. A measure of environment was developed within the study. All instruments were translated according to international guidelines. The potential for bias due to non response and missing data will be examined. After initial analysis using multivariate regression of how the data captured by each instrument relate to impairment and socio-economic characteristics, relationships between the latent traits captured by the instruments will then be analysed using structural equation modelling. Discussion: This study is original in its methods by directly engaging children themselves, ensuring those with learning or communication difficulty are not excluded, and by studying in quantitative

terms the crucial outcomes of participation and quality of life. Specification and publication of this protocol prior to analysis, which is not common in epidemiology but well established for randomised controlled trials and systematic reviews, should avoid the pitfalls of data dredging and post hoc analyses.

4. Herdman, M., Rajmil, L., Ravens-Sieberer, U., Bullinger, M., Power, M., Alonso, J., and the European KIDSCREEN and DISABKIDS Groups. (2002). Expert consensus in the development of a European health-related quality of life measure for children and adolescents: a Delphi study. Acta Pediatrica, 91 (12), 1385-90.

Aim: To determine the level of consensus among experts regarding content, structure and sources of content for a new European measure of health-related quality of life in children and adolescents. Methods: A three-round Delphi questionnaire was sent by e-mail to 24 experts in quality of life measurement in 9 European countries. Consensus was considered reached when > 90% of experts either agreed or disagreed with a given statement, or where median scores were over 6 on a scale of 1-10, and score dispersion was within predefined limits. Results: Completed questionnaires were received from 20 panellists in each round. It was agreed that the new instrument should be a multidimensional, profile measure with 30-49 items covering 5-8 dimensions, which should take no more than 10-15 min to complete. Agreement was also reached on 8 specific dimensions to include in the questionnaire (psychological well-being, self-esteem, body image, cognitive functioning, mobility, energy/vitality, social relations, family/home function). Consensus was against the use of individualized questionnaires. Focus groups with children, parents and workers in the field, literature and instrument reviews were considered appropriate sources for content. Conclusion: Using a Delphi method in this way for the first time showed it to be a feasible and useful method for establishing a conceptual and operational framework for the Kidscreen questionnaire.

5. Malkowska, A., Mazur, J. & Woynarowska, B. (2004). Level of perceived social support and quality of life in children and adolescents. Medycyna Wieku Rozwojowego, VIII (3 Pt 1), 551-566.

The Objective of the study was to determine the influence of perceived social support on health related quality of life (HRQL) in children and adolescents. Material and Methods: Data was obtained through KIDSCREEN study (Screening for and Promotion of Health Related Quality of Life in Children and Adolescents. A European Public Health Perspective) conducted in Poland in 2003, were used. The representative sample comprised 1718 children and adolescents aged 8-18-years. Full version of the KIDSCREEN questionnaire including 52 items grouped into 10 dimensions was used. A short, 3 items Oslo social support scale was used and three levels of social support were defined. Differences between mean values of quality of life scores in three groups of social support were tested using ANOVA method with F-statistics significance and eta square measure of association (h2). Results showed that 46% of Polish children and adolescents reported high, 44% middle and 10% low level of perceived social support. Girls perceived social support better than boys and children better than adolescents. The study showed that the level of perceived social support had essential and positive influence on the quality of life in children and adolescents in all ten dimensions ($p<0.001$). Children with insufficient social support reported lower quality of life in comparison to well supported, especially in Parents Relations and Home Life dimension, $h2=0.186$. Difference between boys and girls and three age groups under study was the highest in the low supported group and then leveled out when social support increased. Conclusion: Social support, especially provided by parents, increases the quality of life in children and adolescents.

6. Mazur, J. & Mierzejewska, E. (2003). Jakosc zycia zwiazana ze zdrowiem dzieci i mlodziezy - koncepcje metody badawcze i wybrane zastosowania. (Health-related quality of life (HRQL) in children and adolescents- concepts, study methods and selected applications. Developmental Period Medicine). Medycyna Wieku Rozwojowego, VII (1 Pt 2), 35-48.

The importance of subjective health measures has increased over the recent years. Prevention of acute and chronic diseases and early intervention in children depend upon availability of measures that can be routinely used for monitoring purposes. Traditional outcome measures (survival, laboratory tests) have limited value when assessing health status of chronically ill persons or screening population. Research on quality of life has a solid methodological background. High importance is attached to psychometric characteristics of developed questionnaires. However, only a few (especially generic) instruments have been developed for children and youth. The aim of the study is: 1) to describe the main concepts and methods in

quality of life research in relation to paediatric practice; 2) to present the KIDSCREEN project sponsored by European Commission, currently in progress. The KIDSCREEN multicenter project is being developed by 13 European countries, including Poland, within the 5th Framework Programme Quality of Life and Management of Living Resources. The project will provide the opportunity to measure the HRQL in children and adolescents across different countries and cultures using a standardized multidimensional instrument developed at the same time in all participating countries. It is expected that it will improve medical, psychological and educational care of children and adolescents and will be very useful in changing the system of preventive health care provided in Polish schools. Applying the KIDSCREEN questionnaire in selected EU candidate countries will anticipate the problems that could affect other countries in the same economic situation.

7. Mazur, J. (2004). Development and initial psychometric analysis of Polish generic quality of life questionnaire for children and adolescents (KIDSCREEN-52). Medycyna Wieku Rozwojowego, VIII (3 Pt 1), 513-534.

BACKGROUND: KIDSCREEN was developed as EC project simultaneously in 13 European countries in ten languages and provided generic measure of quality of life (QOL) in children and adolescents aged 8-18 yrs. An instrument was constructed including 52 items grouped in 10 dimensions, as well as 2 shorter versions, both for children and parents as proxy respondents. AIMS: this study describes the development and initial psychometric evaluation of Polish KIDSCREEN-52 instrument. MATERIAL: the questionnaire was tested in a national mail survey conducted on the representative sample of 1718 children and adolescents aged 8-18 yrs. RESULTS: Polish children and adolescents reported the highest QOL scores for social acceptance and moods and emotions, and the lowest for financial resources and school environment. Gender differences are small in children and but increased in adolescents, especially in self-perception. Cronbach's a ranged from 0.79 to 0.91, and was a little higher in girls than in boys, and higher in adolescents than in younger children. As expected, very high differences were observed between mentally healthy and ill children identified by SDQ (Strengths and Difficulties Questionnaire). To assess the relationship with chronic conditions, the Children with Special Health Care Needs Screener (CSHCN) was applied. Children with special health care needs especially reported lower physical well-being in comparison to healthy children, with moderate effect size. There was a moderate but significant correlation between all ten QOL dimensions measured by KIDSCREEN-52 and other QOL measures applied so far at national level (for example Cantril ladder). CONCLUSION: preliminary results suggested that KIDSCREEN questionnaire could be implemented at the national level and included in health surveys to monitor, evaluate and improve health and subjective well-being in children and adolescents. The Polish version of KIDSCREEN-52 questionnaire is reliable and valid, however, more psychometric analyses should be carried out, national norms should be estimated and some international comparisons be conducted.

8. Rajmil, L., Herdman, M., Fernández de Sanmamed, M.J., Detmar, S., Bruil, J., Ravens-Sieberer, U., Bullinger, M., Simeoni, M.-C., Auquier, P., and the KIDSCREEN Group. (2004). Generic Health-related Quality of Life Instruments in Children and Adolescents: A Qualitative Analysis of Content. Journal of Adolescent Health, 34, 37-45.

Purpose: To determine the extent of differences and similarities in content between heath-related quality of life (HRQOL) instruments for children and adolescents. Methods: A descriptive and explanatory qualitative approach was carried out. Instruments specifically designed for use with children or adolescents were included. To assure the validity of the findings a triangulation of the analysis and "member checking" were performed. Results: Ten questionnaires were analyzed. All of them included items referring to physical, psychological, and social aspects of health. A relatively low number of categories explained the content of the questionnaires. Conclusions: A reasonably coherent notion of HRQOL underlies instruments available for children and adolescents. HRQOL measurement in young people is still in its developmental step.

9. Rajmil L, Alonso J, Berra S, Ravens-Sieberer U, Gosch A, Simeoni MC, Auquier P; KIDSCREEN group. (2006). Use of a children questionnaire of health-related quality of life (KIDSCREEN) as a measure of needs for health care services. J Adolesc Health. May;38(5):511-8.

Purpose: To check if the expected association is observed between children and adolescents' self-perceived health-related quality of life (HRQL) and the use of health care services. Methods: The data come from the

pilot test of a European measure of HRQL for children and adolescents (KIDSCREEN). Children answered the KIDSCREEN 52-item pilot version. Visits to a health professional in the past four weeks and hospitalisation in the past 12 months were collected from parents. A logistic regression model was adjusted to analyse the relationship between the use of health services and HRQL. Results: A total of 2526 children and their parents were included in the analysis. Factors associated to visits in the past four weeks were poor physical well-being (odds ratio [OR] 1.83; 95% confidence interval [CI] 1.42-2.35), and poor school environment (OR 1.32; 95% CI 1.02-1.71). Low scores on moods and emotions was the associated factor to hospitalization in the past 12 months (OR 2.13; 95% CI 1.29-3.81). Conclusions: Children and adolescents are a feasible source for their self-assessment of HRQL. They should be taken into account in health care needs studies.

10. Ravens-Sieberer, U., Gosch, A., Abel, T., Auquier, P., Bellach, B.-M., Bruil, J., Dür, W., Rajmil, L. & the European KIDSCREEN Group. (2001). Quality of life in children and adolescents: a European public health perspective. Social and Preventive Medicine, 46, 297-302.

Objectives: The measurement of health-related quality of life (HRQOL) is increasingly important as a means of monitoring population health status over time, of detecting sub-groups within the general population with poor HRQOL, and of assessing the impact of public health interventions within a given population. At present, no standardised instrument exists which can be applied with equal relevance in pediatric populations in different European populations. The collaborative European KIDSCREEN project aims to develop a standardised screening instrument for children's quality of life which will be used in representative national and European health surveys. Participants of the project are centres from Austria, France, Germany, Netherlands, Spain, Switzerland, and United Kingdom. By including the instrument in health services research and health reporting, it also aims at identifying children at risk in terms of their subjective health, thereby allowing the possibility of early intervention. Methods: Instrument development will be based on constructing a psychometrically sound HRQOL instrument taking into account the existing state of the art. Development will centre on literature searches, expert consultation (Delphi Methods) and focus groups with children and adolescents (8-17 years). According to international guidelines, items will be translated into the languages of the seven participating countries for a pilot test with 2,100 children and their parents in Europe. The final instrument will be used in representative mail and telephone surveys of HRQOL in 1,800 children and their parents per country (total n = 25,200) and normative data will be produced. The potential for implementing the measurement tool in health services and health reporting will also be evaluated in several different research and public health settings. The final analysis will involve national and cross cultural-analysis of the instrument. Results: The international, collaborative nature of the KIDSCREEN project means it is likely to provide many challenges in terms of producing an instrument which is conceptually and linguistically appropriate for use in many different countries, but it will also provide the opportunity to develop, test and implement the first truly cross-national HRQOL instrument developed for use in children and adolescents. This will help to contribute to a better understanding of perceived health in children and adolescents and to identify populations at risk.

11. Ravens-Sieberer, U., Gosch, A., Rajmil, L., Erhart, M., Bruil, J., Duer, W., Auquier, P., Power, M., Abel, T., Czemy, L., Mazur, J., Czimbalmos, A., Tountas, Y., Hagquist, C., Kilroe, J. and the European KIDSCREEN Group. (2005). KIDSCREEN-52 quality-of-life measure for children and adolescents. Expert Review of Pharmacoeconomics & Outcomes Research, 5 (3), 353-364.

This study describes the development and reports the first psychometric results of the European KIDSCREEN-52 generic health-related quality-of-life questionnaire for children and adolescents. The KIDSCREEN-52, including ten dimensions, was applied in a European survey involving 12 countries (i.e., Austria, Switzerland, Czech Republic, Germany, Greece, Spain, France, Hungary, The Netherlands, Poland, Sweden and the UK) and 22,110 children and adolescents aged between 8 and 18 years of age. Questionnaire development included a literature search, expert consultation, and focus group discussions with children and adolescents. After definition of dimensions and collection of items, a translation process following international translation guidelines, cognitive interviews and a pilot test were performed. Analysis regarding psychometric properties showed Cronbach-α ranged from 0.77 to 0.89. Correlation coefficients between KINDLR and KIDSCREEN-52 dimensions were high for those assessing similar constructs (r = 0.51–0.68). All KIDSCREEN-52 dimensions showed a gradient according to socioeconomic status and most dimensions showed a gradient according to psychosomatic health complaints. The first results demonstrate

that the KIDSCREEN-52 questionnaire is a promising cross-cultural measure of health-related quality-of-life assessment for children and adolescents in Europe.

12. Rigby, M., Ravens-Sieberer, U., Qinlan, A., and Macfarlane, A. (2002). The Span in Information from Researching New Tools to Accessible Presentation - Experience from Child Health. In: W. Kirch (ed.). Bridging the Gap between Research and Policy in Public Health - Information, Promotion, and Training. Springer, Heidelberg.

13. Serra-Sutton V, Rajmil L, Berra S, Herdman M, Aymerich M, Ferrer M, Robitail S, Simeoni MC. [Reliability and validity of the Spanish version of the health and quality-of-life questionnaire, the Vecu et Sante Percue de l'Adolescent (VSP-A)] Aten Primaria. 2006 Mar 15;37(4):203-8. Spanish.

Objective: To assess the psychometric properties of the Spanish version of the Vecu et Sante Percue de l'Adolescent (VSP-A) in terms of reliability and validity. Design: Cross-sectional study. Setting: Pilot study parallel to the European Kidscreen project. Two secondary schools, one public and one private, were selected for their suitability in Barcelona and Gerona (Catalonia, Spain). The sample unit was the classroom. Participants: A sample of 354 adolescents aged 12 to 18 years old was selected. Main Measurements: The Spanish VSP-A questionnaire was administered, and again a week later to check its test-retest stability. The KINDL questionnaire was administered in parallel. Results: The response rate was 82% (n=291). The Spanish version of the VSP-A showed good internal consistency and acceptable test-retest reliability (Cronbach's alpha: 0.69-0.92, intraclass correlation coefficient [ICC]: 0.69-0.74) in most domains. Domains measuring a similar concept in the VSP-A and KINDL had closer correlation coefficients than those measuring different constructs ($P<.05$), which demonstrates its convergent validity. Girls had worse self-perceived health than boys (lower vitality, physical and emotional well-being and self-esteem, and a lower general score on the VSP-A; $p<.01$). These differences were more obvious in older teens (16-18 years old). Conclusions: The Spanish VSP-A showed good psychometric properties and results were consistent with the original French version. The results mean we have an adequate HRQL instrument for teens and for use in primary care and public health.

14. von Rueden, U., Gosch, A., Rajmil, L., Bisegger, C., Ravens-Sieberer, U., and the KIDSCREEN Group. (2006). Socioeconomic determinants of health-related quality of life in childhood and adolescence: results from a European study, Journal of Epidemilology and Community Health., 60(2), 130-135.

Study Objective: The objective of this study was to investigate the impact of two different socioeconomic status (SES) measures on child and adolescent self reported health related quality of life (HRQoL). The European KIDSCREEN project aims at simultaneous developing, testing, and implementing a generic HRQoL instrument. Design and Setting: The pilot version of the questionnaire was applied in school surveys to students from 8 to 18 years of age, as well as to their parents, together with such determinants of health status as two SES indicators, the parental educational status and the number of material goods in the family (FAS, family affluence scale). Participants: Students from seven European countries: 754 children (39.8%; mean: 9.8 years), and 1142 adolescents (60.2 %; mean: 14.1 years), as well as their respective parents. Main Results: In children, a higher parental educational status was found to have a significant positive impact on the KIDSCREEN dimensions: physical wellbeing, psychological wellbeing, moods and emotions, bullying and perceived financial resources. Increased risk of low HRQoL was detected for adolescents in connection with their physical wellbeing. Family wealth plays a part for children's physical wellbeing, parent relations and home life, and perceived financial resources. For adolescents, family wealth furthermore predicts HRQoL on all KIDSCREEN dimensions. Conclusions: There is evidence to suggest that exposure to low parental educational status may result in a decreased HRQoL in childhood, whereas reduced access to material (and thereby social) resources may lead to a lower HRQoL especially in adolescence.

Examples of the KIDSCREEN-52 HRQoL questionnaire for children and adolescents (8-18 years)

Thinking about the last week...

1.	***Examples: Physical Well-Being Dimension***					
	Have you felt fit and well?	not at all	slightly	moderately	very	extremely
	Have you been physically active (e.g. running, climbing, biking)?	not at all	slightly	moderately	very	extremely
2.	***Examples: Psychological Well-Being Dimension***					
	Has your life been enjoyable?	not at all	slightly	moderately	very	extremely
	Have you felt satisfied with your life?	not at all	slightly	moderately	very	extremely
3.	***Examples: Moods and Emotions Dimension***					
	Have you felt that you do everything badly?	never	seldom	quite often	very often	always
	Have you felt under pressure?	never	seldom	quite often	very often	always
4.	***Examples: Self-Perception Dimension***					
	Have you been happy with the way you are?	never	seldom	quite often	very often	always
	Have you felt jealous of the way other girls and boys look?	never	seldom	quite often	very often	always
5.	***Examples: Autonomy Dimension***					
	Have you had enough time for yourself?	never	seldom	quite often	very often	always
	Have you been able to choose what to do in your free time?	never	seldom	quite often	very often	always
6.	***Examples: Parent Relations and Home Life Dimension***					
	Have your parent(s) had enough time for you?	never	seldom	quite often	very often	always
	Have you been able talk to your parent(s) when you wanted to?	never	seldom	quite often	very often	always

		never	seldom	quite often	very often	always
7.	***Examples: Social Support and Peers Dimension***					
	Have you had fun with your friends?	○	○	○	○	○
	Have you been able to rely on your friends?	○	○	○	○	○
8.	***Examples: School Environment Dimension***					
	Have you enjoyed going to school?	○	○	○	○	○
	Have you got along well with your teachers?	○	○	○	○	○
9.	***Examples: Social Acceptance (Bullying) Dimension***					
	Have you been afraid of other girls and boys?	○	○	○	○	○
	Have other girls and boys made fun of you?	○	○	○	○	○
10.	***Examples: Financial Resources Dimension***					
	Have you had enough money to do the same things as your friends?	○	○	○	○	○
	Have you had enough money for your expenses?	○	○	○	○	○

KINDL

The KINDL®-questionnaire with 24 items it is a short, methodologically suitable psychometrically sound and flexible measure to assess health related quality of life in children. The questionnaire can be completed both by children and adolescents, and also by their parents (Proxy-version).

The KINDL®-questionnaire is available for different age groups and stages of : 4 - 7 years, 8 - 11 years, 12 - 16 years, Parents. A paper-pencil version and a computer assisted version (CAT-SCREEN) is available.

The KINDL®-questionnaire can be used for both healthy and ill children (generic approach) and can be augmented by disease-specific modules: Obesity, Bronchial asthma, Atopic Dermatitis, Cancer, Diabetes. The KINDL® questionnaire has so far been used and checked in a number of different types of scientific studies involving over 5,000 healthy and chronically ill children as well as their parents, over a period of up to 2 years.

Originally developed by Bullinger 1994, revised by Ravens-Sieberer & Bullinger 1998.

Abbreviated Name: KINDL
Author(s): Ulrike Ravens-Sieberer, Monika Bullinger
Purpose: Designed to obtain a self-report and an external assessment of health-related quality of life in children and adolescents in a wide range of ages and independently of current health status
Population: Pediatrics (Kiddy-KINDL for children aged 4 to 7 and Kid-KINDL for children aged 8 to 12)and Adolescents (Kiddo-KINDL for adolescents aged 13 to 16)
Age Range : 4 - 16 years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-administered Two proxy-administered version are also available: the Kiddy-KINDL for parents (4-7) and the KINDL for parents (8 to 16)
Time required:	5-15 minutes
Response Options:	Likert scale
Scoring:	Global score Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 24 + a disease module (6 items).
Specific-disease modules are available for the illnesses obesity, bronchial asthma, atopic dermatitis and diabetes A 12-item short form has also been developed.
Original Language: German
Existing Translations : English, French, Greek, Italian, Spanish, Dutch

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Contact for information and permission to use:

Ulrike Ravens-Sieberer, Ph.D., M.P.H.
Head Child and Adolescent Health
Robert Koch Institute
Stresemannstr. 90
D - 10963 Berlin
Phone: +49 30 4547 3436
Fax: +49 30 4547 3531
E-Mail: Ravens-SiebererU@rki.de

Dimensions covered by the questionnaire :

- Functional capacity in everyday life
- Psychological well being
- Social relationships
- Physical state

Key References:

1. Ravens-Sieberer U. Bullinger M. Assessing quality of life in chronically ill children with the German KINDL : first psychometric and content analytical results. Quality of Life Research 7(5) :399-407, 1998

Health-related quality of life is increasingly being considered as a relevant end-point and outcome criterion in evaluating the effects of medical treatment. While in adults quality of life instruments have been developed in terms of generic as well as disease-specific measures, quality of life assessment and children is a relatively new area. The current paper describes the application of a German generic quality of life instrument for children (the KINDL) in a group of 45 chronically ill children suffering from diabetes or asthma in comparison to 45 age- and gender-matched healthy children. The results of psychometric testing in these populations showed that the German KINDL is a reliable, valid and practical instrument to assess the health-related quality of life of children which should be supplemented by disease-specific modules and needs to be further tested in clinical populations.

2. Bullinger, M. (1994). KINDL a questionnaire for health-related quality of life assessment in children. Zeitschrift für Gesundheitspsychologie, 1, 64-77.

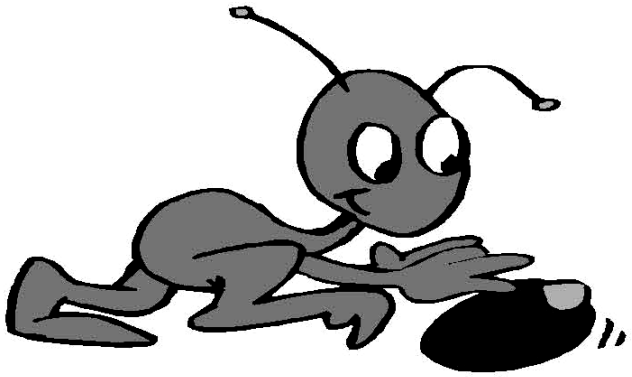
KINDL^{R}

English

Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents

Revised Version

Manual



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1 Information about the KINDL^R Questionnaire

While most quality of life measures for children have been developed in the English language and then translated in a further, methodologically elaborate step (Ravens-Sieberer and Cieza, 2000), the generic KINDL^R Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents represents a German-language measure (originally developed by Bullinger et al. 1994, revised by Ravens-Sieberer & Bullinger 1998a, 1998b), for use in clinical populations but also with healthy children and adolescents.

The KINDL^R Questionnaire for Children and Adolescents described below was developed and tested with a view to remedying the discrepancy between the urgency of the subject 'Quality of Life in Children and Adolescents' and the lack appropriate measures (Ravens-Sieberer, 2000). In developing it, the goal was to design a short, methodologically suitable and flexible set of instruments which could be completed both by children/adolescents and by their parents, which was available for different age groups and stages of development, which could be used for healthy and ill children (generic approach), which could be extended by means of specific modules (e.g. for different classes of diseases) and which could be used in different types of study, namely: a) epidemiological studies on the situation of children and adolescents in the Federal Republic of Germany, b) clinical studies dealing with the effects of therapeutic measures on the quality of life of acutely and chronically ill children, and c) in rehabilitation, looking into the effects of rehabilitation programmes – and in each case from the perspective of the children and of their parents.

The questionnaire has so far be used and tested in a number of studies over a period of up to three years involving over 3000 healthy and chronically ill children as well as their parents. The psychometric results reveal a high degree of reliability (Cronbach's $\alpha \geq .70$ for most of the sub-scales and samples) and a satisfactory convergent validity of the procedure, beyond which the acceptance of the measure by children and adolescents is high (Ravens-Sieberer, 1998). The questionnaire has been able to distinguish between children with different physical disorders and under different types of strain. Overall, the KINDL^R has proved to be a flexible, modular, psychometrically acceptable method of measuring quality of life in children by means of a central module covering generic aspects in children's quality of life while also measuring the specific burdens associated with diseases in childhood via additional modules. Age-specific versions take into account the changes in the quality of life dimensions in the course of child development.

1.1 Structure of the Questionnaire

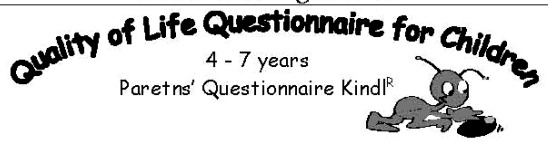
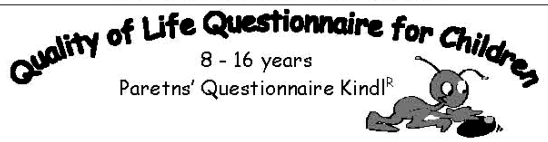
The KINDL^R questionnaire satisfies the demand for taking into account progress during child development and the principle of patient-generated data collection by providing different versions of the questionnaire for different age groups and both a self-report version and a proxy version. The common practice of modifying a measure originally designed for adults to make it suitable for children, was avoided here. With the KINDL^R questionnaire an original German-language measure is available that was specifically designed and validated for children. The psychometric testing of the KINDL^R shows that a procedure has been developed that can be used in epidemiological, clinical and rehabilitation research studies; the use of the KINDL^R questionnaire in the context of health care planning is increasingly under discussion.

1.1.1 Self-assessment and external assessment by age groups

Three versions of the KINDL^R questionnaire are available as self-report measures for different age groups:

Kiddy-KINDL^R for children aged 4 to 7	Kid-KINDL^R for children aged 8 to 12	Kiddo-KINDL^R for adolescents aged 13 to 16

In addition, the questionnaire is available in two proxy versions for parents (4 - 7-year-olds and 8 - 16-year-olds):

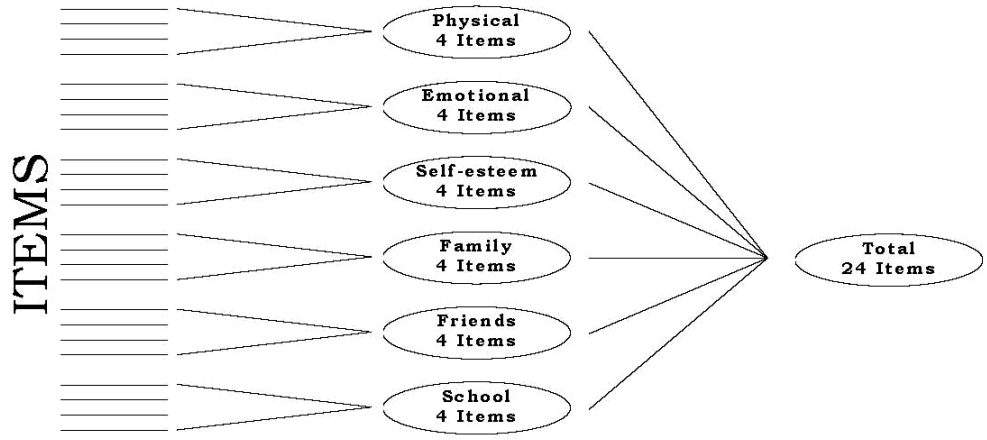
Kiddy-KINDL^R for Parents of children aged 4 to 7	KINDL^R for Parents of children and adolescents
	

Furthermore, a **short form of the KINDL^R** (12 items) has been developed, as well as a series of **disease-specific modules** (obesity, asthma, atopic dermatitis and diabetes). The questionnaire is also available in the **languages** English, French, Dutch, Russian, Turkish, Italian and Spanish. A **Computer-Assisted Touch Screen version (CAT-Screen)** of the questionnaire is available as well.

1.1.2 Structure of the scales

The KINDL^R questionnaire consists of 24 Likert-scaled items associated with six dimensions: physical well-being, emotional well-being, self-esteem, family, friends and everyday functioning (school or nursery school/kindergarten). The sub-scales of these six dimensions can be combined to produce a total score.

Figure 1: Structure of the Sub-Scales Included in the KINDL^R Questionnaire



1.1.3 "Disease" module

All versions of the KINDL^R contain an additional sub-scale entitled "Disease", whose items can be completed in case of prolonged illness or hospitalisation. The additional sub-scale consists of a filter question and six items which measure the child's quality of life with respect to his or her illness. In addition, disease-specific modules are available for the illnesses obesity, bronchial asthma, atopic dermatitis and diabetes.

1.1.4 Kiddy-KINDL^R interview version for children and additional questions for parents

On account of the particular difficulties associated with interviewing young children, the structure of the Kiddy-KINDL^R differs from that of the other questionnaires (Kid/Kiddo). In the self-report version, it only consists of twelve items, two for each dimension. This means that no sub-scale scores can be calculated for the individual dimensions but only a total score. The additional questions on "Disease" are, on the other hand, included in full. The response categories of the Kiddy-KINDL^R cover 3 levels (1 = never, 2 = sometimes, 3 = very often), the children are to be questioned in a face-to-face interview.

The parents' version of the Kiddy-KINDL^R with its 24 items in 6 dimensions corresponds in structure to the parents' version of the KINDL^R for 8 to 16-year-old children and teenagers. However, in order to make up for the potentially lower information content of the self-

reported responses by young children, the parents' version of the Kiddy-KINDL^R contains a further 22 items which can be treated as a sub-scale in their own right.

1.2 Structure of the Sub-Scales and Classification of Items

1.2.1 Self-report versions

Kiddy-KINDL^R (4 to 7-year-olds) Children's Version (Interview)	Kid-KINDL^R (8 to 12-year-olds) Children's Version	Kiddo-KINDL^R (13 to 16-year-olds) Teenagers' Version
Physical Well-Being		
1. ... I felt ill	1. ... I felt ill	1. ... I felt ill
2. ... I had a headache or tummy-ache	2. ... I had a headache or tummy-ache	2. ... I was in pain
	3. ... I was tired and worn-out	3. ... I was tired and worn-out
	4. ... I felt strong and full of energy	4. ... I felt strong and full of energy
Emotional Well-Being		
3. ... I had fun and laughed a lot	5. ... I had fun and laughed a lot	5. ... I had fun and laughed a lot
4. ... I was bored	6. ... I was bored	6. ... I was bored
	7. ... I felt alone	7. ... I felt alone
	8. ... I was scared	8. ... I felt scared or unsure of myself
Self-Esteem		
5. ... I was proud of myself	9. ... I was proud of myself	9. ... I was proud of myself
6. ... I felt pleased with myself	10. ... I felt on top of the world	10. ... I felt on top of the world
	11. ... I felt pleased with myself	11. ... I felt pleased with myself
	12. ... I had lots of good ideas	12. ... I had lots of good ideas
Family		
7. ... I got on well with my parents	13. ... I got on well with my parents	13. ... I got on well with my parents
8. ... I felt fine at home	14. ... I felt fine at home	14. ... I felt fine at home
	15. ... We quarrelled at home	15. ... We quarrelled at home
	16. ... My parents stopped me from doing certain things	16. ... I felt restricted by my parents
Friends		
9. ... I played with friends	17. ... I played with friends	17. ... I did things together with my friends
10. ... I got along well with my friends	18. ... Other kids liked me	18. ... I was a "success" with my friends
	19. ... I got along well with my friends	19. ... I got along well with my friends
	20. ... I felt different from other children	20. ... I felt different from other people
Everyday Functioning (School or Nursery School/Kindergarten)		
11. ... I coped well with the assignments set in nursery school/kindergarten	21. ... doing my schoolwork was easy	21. ... doing the schoolwork was easy
	22. ... I enjoyed my lessons	22. ... I found school interesting
12. ... I enjoyed nursery school/ kindergarten	23. ... I looked forward to the weeks ahead	23. ... I worried about my future
	24. ... I was afraid of bad marks or grades	24. ... I worried about getting bad marks or grades

Kiddy-KINDL^R (4 to 7-year-olds) Children's Version	Kid-KINDL^R (8 to 12-year-olds) Children's Version	Kiddo-KINDL^R (13 to 16-year-olds) Teenagers' Version
"Disease" Module		
13. Are you staying in hospital just now or do you have some long-term illness? (Filter question)	25. Are you staying in hospital just now or do you have some long-term illness? (Filter question)	25. Are you staying in hospital just now or do you have some long-term illness? (Filter question)
14. ... I was afraid that my illness might get worse	26. ... I was afraid that my illness might get worse	26. ... I was afraid that my illness might get worse
15. ... I was sad because of my illness	27. ... I was sad because of my illness	27. ... I was sad because of my illness
16. ... I was able to cope well with my illness	28. ... I was able to cope well with my illness	28. ... I was able to cope well with my illness
17. ... my parents treated me like a baby because of my illness	29. ... My parents treated me like a baby because of my illness	29. ... My parents treated me like a baby because of my illness
18. ... I avoided others to notice my illness	30. ... I avoided others to notice my illness	30. ... I avoided others to notice my illness
19. ... I missed something at nursery school/kindergarten because of my illness	31. ... I missed something at school because of my illness	31. ... I missed something at school because of my illness

1.2.2 Parents' versions

Kiddy-KINDL^R (4 to 7-year-olds) Parents' Version	KINDL^R (8 to 16-year-olds) Parents' Version
Physical Well-Being	
1. … my child felt ill	1. … my child felt ill
2. … my child had a headache or tummy-ache	2. … my child had a headache or tummy-ache
3. ... my child was tired and worn-out	3. ... my child was tired and worn-out
4. ... my child felt strong and full of energy	4. ... my child felt strong and full of energy
Emotional Well-Being	
5. ... my child had fun and laughed a lot	5. ... my child had fun and laughed a lot
6. ... my child didn't feel much like doing anything	6. ... my child didn't feel much like doing anything
7. ... my child felt alone	7. ... my child felt alone
8. ... my child felt scared or unsure of itself	8. ... my child felt scared or unsure of itself
Self-Esteem	
9. ... my child was proud of himself	9. ... my child was proud of himself
10. ... my child felt on top of the world	10. ... my child felt on top of the world
11. ... my child felt pleased with himself	11. ... my child felt pleased with himself
12. ... my child had lots of good ideas	12. ... my child had lots of good ideas
Family	
13. ... my child got on well with us as parents	13. ... my child got on well with us as parents
14. ... my child felt fine at home	14. ... my child felt fine at home
15. ... we quarrelled at home	15. ... we quarrelled at home
16. ... my child felt that I was bossing him around	16. ... my child felt that I was bossing him around
Friends	
17. ... my child played with friends	18. ... my child did things together with friends
18. ... my child was liked by other kids	19. ... my child was liked by other kids
19. ... my child got along well with his friends	20. ... my child got along well with his friends
20. ... my child felt different from other children	21. ... my child felt different from other children
Everyday Functioning (School or Nursery School/Kindergarten)	
21. ... my child coped well with the assignments set in nursery school/ kindergarten	22. ... my child easily coped with schoolwork
22. ... my child enjoyed the nursery school/ kindergarten	23. ... my child enjoyed the school lessons
23. ... my child looked forward to nursery school/kindergarten	24. ... my child worried about his future
24. ... my child made lots of mistakes when doing minor assignments or homework	25. ... my child was afraid of bad marks or grades

Kiddy-KINDL^R (4 to 7-year-olds) Parents' Version
Additional Items "Kiddy Parents"
25. ... my child was moody and whined a lot
26. ... my child had a healthy appetite
27. ... I managed to show patience and understanding towards my child
28. ... my child felt under pressure
29. ... my child slept soundly
30. ... my child romped around and was very active
31. ... my child kept bursting into tears
32. ... my child was cheerful and in a good mood
33. ... my child was alert and able to concentrate well
34. ... my child was easily distracted and absent- minded
35. ... my child enjoyed being with other children
36. ... I had to give my child a telling-off
37. ... I praised my child
38. ... my child had problems with teachers, kindergarten staff or other child-minders
39. ... my child was nervous and fidgety
40. ... my child was lively and energetic
41. ... my child complained of being in pain
42. ... my child was sociable and out- going
43. ... my child succeeded at everything he set out to do
44. ... my child became dissatisfied easily
45. ... my child cried bitterly
46. ... my child lost his temper quickly

Kiddy-KINDL^R (4 to 7-year-olds) Parents' Version	KINDL^R (8 to 16-year-olds) Parents' Version
"Disease" Module	
47. Is your child staying in hospital just now or does it have a long-term illness? (Filter question)	25. Is your child staying in hospital just now or does it have a long-term illness? (Filter question)
48. ... my child was afraid that the illness might get worse	26. ... my child was afraid that the illness might get worse
49. … my child was sad because of the illness	27. … my child was sad because of the illness
50. ... my child was able to cope well with his illness	28. ... my child was able to cope well with his illness
51. ... we treated our child as though he were younger, because of the illness	29. ... we treated our child as though he were younger, because of the illness
52. ... my child avoided others to notice his illness	30. ... my child avoided others to notice his illness
53. ... my child missed something at nursery school/kindergarten because of his illness	31. ... my child missed something at school because of his illness

1.3 Psychometrics

The psychometric tests conducted on the questionnaire and discussed here include the testing of its reliability (internal consistency, i.e. Cronbach's alpha) and validity (factorial validity, convergent validity, discriminant validity and sensitivity).

The first steps in the psychometric calculations consisted of an item analysis and a *reliability analysis* of the KINDL^R questionnaire using the Multitrait Analysis Program of the New England Medical Center at Tuffts University in Boston (MAP) (Hays et al., 1988). The MAP program uses Campbell's multitrait approach and permits a confirmatory test of the questionnaire's postulated scale structure. For each item it delivers the magnitude of the correlation between the item and the overall scale (adjusted for overlap) as well as the success statistics for the frequency of cases displaying a higher or significantly higher correlation of an item as compared with the correlation with other scales. These success statistics, also known as scale fit, can take on values between 0% and an optimum 100%, and indicate the *factorial validity* of the questionnaire on an item level. Beyond this, the internal consistency coefficient Cronbach's alpha is given.

The *convergent validation* was done by correlating the sub-scales of the KINDL^R questionnaire with comparable well-being scales. The *discriminant validity* was determined by distinguishing subgroups within the survey population according to criteria that suggested a difference in their quality of life assessment.

The analysis of the psychometric quality of the questionnaire was performed using two samples:

Sample 1

1501 pupils in the fourth and eighth grade completed the short version (12 items) of the KINDL^R in the course of the regular school medical check-ups in Hamburg. The fourth graders (n=918) were an average of 9.7 years old, the eight grade teenagers (n=583) 14.1 years old. The sample consisted of 48.3 % girls and 51.7 % boys (Ravens-Sieberer et al., 2000a).

Sample 2

1050 children and adolescents from 7 German rehabilitation clinics completed the KINDL^R questionnaire before embarking on a rehabilitation programme. The sample consisted of 50.7 % girls and 49.3 % boys. Their average age was 12.6 years; the sample comprised three diagnostic groups: bronchial asthma (n=254), atopic dermatitis (n=163) and obesity (n=633) (Ravens-Sieberer et al., 2000b).

1.3.1 Structure of sub-scales, reliability and factorial validity

The analysis of the data from the KINDL^R questionnaires completed by chronically ill children and adolescents and their parents (Sample 2, n=1050) using the MAP program revealed a good utilisation of the scale width with floor and ceiling effects generally below 10%. The scale fit was above 80% for all sub-scales. The reliability was checked by confirmatory testing, Cronbach´s alpha as a measure of internal consistency reached values of around α =.70 for most sub-scales, while the overall scale displayed a consistency coefficient of over α =.80.

Table 1: Structure of Sub-Scales and Reliability (children, data transformed 0-100)

Sub-scale	n	No. of items	Mean	Standard deviation	Floor %	Ceiling %	Scale fit %	Internal consistency α
Physical	915	4	70.63	17.31	.1	4.8	87.5	.63
Emotional	915	4	80.31	14.88	.0	9.7	91.7	.68
Self-esteem	915	4	57.88	20.56	.4	1.7	100.0	.75
Family	915	4	77.69	17.13	.0	10.5	100.0	.76
Friends	915	4	71.44	18.25	.3	7.7	91.7	.74
School	915	4	64.56	21.88	.1	3.4	91.7	.64
Total	***915***	*24*	*70.58*	***11.94***	*.0*	***.0***	*94.2*	***.84***
Disease module	915	6	77.71	17.96	.0	11.9	91.7	.66

Table 2: Structure of Sub-Scales and Reliability (parents, data transformed 0-100)

	n	No. of items	Mean	Standard deviation	Floor %	Ceiling %	Scale fit %	Internal consistency α
Physical	899	4	64.00	18.44	.0	2.6	83.3	.70
Emotional	899	4	69.44	17.75	.0	4.2	100.0	.76
Self-esteem	899	4	56.06	19.50	.2	2.1	100.0	.77
Family	899	4	79.38	17.75	.1	5.9	100.0	.81
Friends	899	4	67.94	18.13	.0	4.1	87.5	.74
School	899	4	65.63	18.06	.1	3.6	95.8	.62
Total	***899***	*24*	*56.58*	*13.15*	***.0***	***.0***	***95.8***	*.89*
Disease module	899	6	69.83	18.88	.0	6.1	88.9	.72

1.3.2 Convergent validity

In terms of convergent validity, the KINDL^R sub-scales were correlated both with the subjective health dimensions of the Child Health Questionnaire (Landgraf et al., 1999) and the SF-36 (Bullinger & Kirchberger, 1998) and with the "Life Satisfaction" questionnaire adapted for children (FLZM; Herschbach & Henrich, 2000). It was found that the KINDL^R total score displayed a high correlation particularly with the "General Well-Being" sub-scale of the Child Health Questionnaires and with the "Vitality" and "Emotional Well-Being" sub-scales of the SF-36 as well as the FLZM (r>.60). Since the KINDL^R aims more at the psychosocial than the physical aspects of health-related quality of life, the correlation of the KINDL^R sub-scales with physical aspect of quality of life ("Global Health" and "Physical Activities" scale of the Child Health Questionnaire) are lower, as expected.

Table 3: Convergent Validity (Pearson r)

KINDL^R sub-scale	CHQ Global health	CHQ General well-being	CHQ Physical activities	SF-36 Vitality	SF-36 Emotional well-being	FLZ Life satisfaction
Physical	.34	.52	.37	.55	.44	.40
Emotional	.26	.59	.31	.48	.56	.45
Self-Esteem	.32	.50	.23	.46	.44	.53
Family	.15	.37	.12	.26	.32	.47
Friends	.19	.48	.37	.42	.41	.46
School	.28	.42	.15	.31	.39	.41
Total	**.40**	**.72**	**.39**	**.62**	**.64**	**.69**
Disease module	.36	.51	.37	.41	.43	.45

1.3.3 Discriminant validity

The initial results of the use of the KINDL^R questionnaire on chronically ill children show that the measure is able to distinguish between differences in the impairment of health-related quality of life in children with different diseases (asthma, atopic dermatitis, obesity) both on a sub-scale level and in terms of its total score (see Figure 2).

Table 4: Sub-scale Means for Different Samples

	Physical	Emo-tional	Self-esteem	Family	Friends	School	Total	Disease
Healthy (n=1501)	75.56	83.01	66.6	83.99	78.18	73.13	76.75	
Asthma (n=254)	71.02	82.35	63.68	79.33	76.8	67.34	73.38	82.28
Atopic dermatitis (n=163)	74.94	81.44	62.63	80.76	77.72	68.55	74.41	78.29
Obesity (n=633)	70.1	79.28	54.71	76.78	70.84	62.43	68.93	75.45

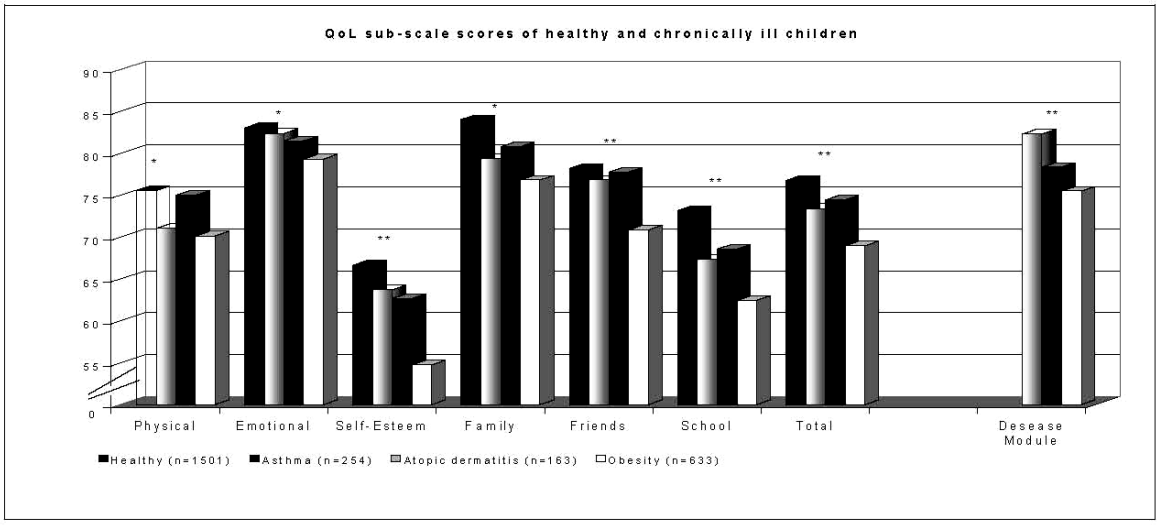


Figure 2: Discriminant Validity of the KINDL^R Questionnaire (*p ≤ .05, **p ≤ .01)

1.3.4 Sensitivity

In a study dealing with the rehabilitation of chronically ill children (cf. Sample 2, Section 1.3) 1050 children completed the KINDL^R questionnaire at the beginning and the end of a six-week in-patient rehabilitation programme.

Four of the six KINDL^R sub-scales could be applied both before and after rehabilitation (School and Family had to be omitted because they could not be assessed). For all three groups of chronically ill children (asthma, atopic dermatitis and obesity), significant changes between before and after rehabilitation were apparent, particularly on the KINDL^R dimensions Physical, Self-Esteem, Friends and Total Score, as well as on disease-specific asthma, atopic dermatitis and obesity modules and the additional Disease module.

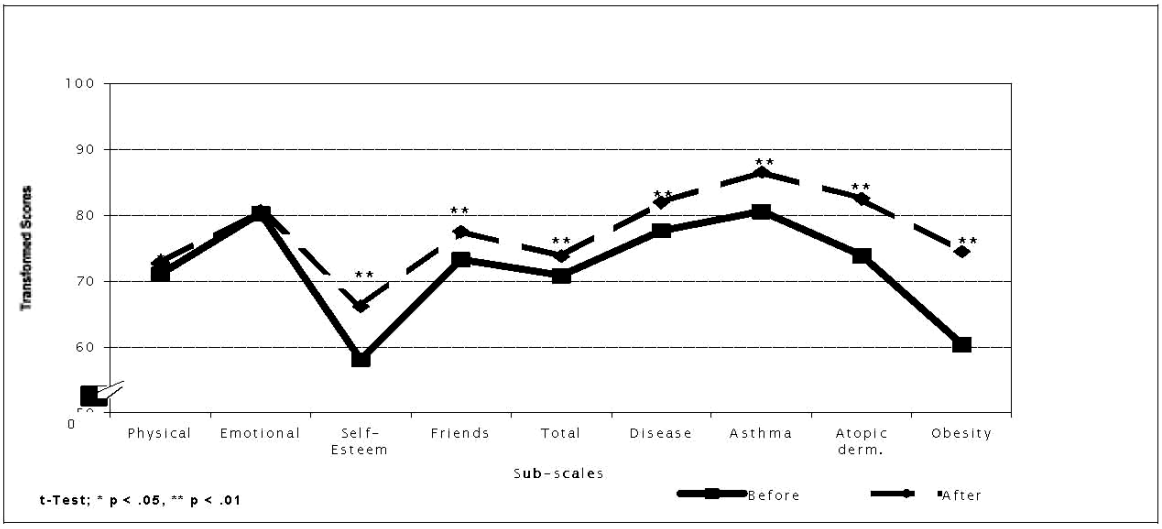


Figure 3: KINDL Sub-Scale Differences by Time of Measurement . T-Test; * p ≤ .05, ** p ≤ .01

For the overall group, the Kazis effect size varied between d=.02 and .69, the changes between before and after rehabilitation were particularly pronounced for the dimension Self-Esteem and also in terms of the Total Score. Looking at the individual diagnostic groups, asthma and atopic dermatitis displayed effects in the field of the changes in chronic-generic and the asthma-specific module. In the obesity group, distinct effects were observed in the field of changes in Self-Esteem, Total Score and the disease-specific obesity module d=.69.

Table 5: Strength of Effect t1 – t2 (KAZIS effect size)

KINDL sub-scale	No. of items	d total	d asthma	d neurod.	d adipos.
Physical	4	.10	.08	.02	.13
Emotional	4	.03	.00	.11	.02
Self-Esteem	4	.40	.14	.12	.56
Family	4				
Friends	4	.23	.18	.20	.26
School	4				
Total	*24*	*.24*	*.06*	*.11*	.33
Disease module	6	.24	.07	.08	.33
Disease-specific module	12		.51	.50	.82

1.4 Execution

The KINDL^R questionnaire was designed in order to obtain a self-assessment and an external assessment of health-related quality of life in children and adolescents in a wide range of ages and independently of current health status. For each item, the children and teenagers are required to mark the response that comes closest to their own personal experiences.

Parents are asked to complete the KINDL^R questionnaire as proxies, i.e. they are asked to judge the children's quality of life from their own point of view (Ravens-Sieberer et al., in press a).

In developing the KINDL^R questionnaire, a great deal of emphasis was placed on ensuring that the questions and instructions are straightforward and easy to understand. Both the self-assessment version and the version for external assessment include the necessary instructions for completion and can therefore be answered by children, adolescents and parents without any further assistance from other persons. It is not necessary for a supervisor to be constantly present while the KINDL^R questionnaire is being completed although this may be advisable in the case of children whose reading skills are perhaps not of a necessary standard. In such cases, the KINDL^R questionnaire can be administered in the form of an interview (face-to-face or by telephone). Experiences and results so far indicate a high practicability of telephone interviews (Bullinger u. Bahner, 1997).

The time needed to complete the KINDL^R questionnaire, as measured empirically in a series of studies, varies between 5 and 15 minutes, depending on the age of the children/teenagers. The average time for completion is 10 minutes, whereby younger children usually require longer to complete the questionnaire. There is no time limit for completing the questionnaire, however for the self-assessed version it is advisable to have the individual questionnaires checked by an authorised person for completeness, since the analysis of the questionnaire may be jeopardised if only a few items are answered.

If both the self-assessment and external assessment versions of the KINDL^R questionnaire are used, it is crucial to ensure that the children/teenagers and parents complete the questionnaires independently of one another!

One means of conducting surveys using the KINDL^R questionnaire, beyond the simple paper-and-pencil questionnaire form, is to include the KINDL^R questionnaire in computer-aided diagnoses and to instruct the children/teenagers on how to enter their own data using a laptop computer. This option is available via the CAT-Screen program (Ravens-Sieberer et al., in press b). In the long term, the approach of a computer-assisted, multimedia version of the KINDL^R questionnaire would seem sensible particularly in the clinical field, as a routine means of documenting initial and final check-ups (on admission and prior to being discharged) in children and adolescents.

1.5 Interpretation and Reference Values

The scores achieved on the individual KINDL^R sub-scales and the KINDL^R total score represent a quantification of the subject's health-related quality of life from the respondent's point of view. There are three ways of interpreting these scores:

First of all, the values within the individual sub-scales can be studied directly. The distance from the possible limits (maximum and minimum achievable values) can give a first indication of a respondent's self-assessment.

The second means of interpretation consists in comparing the sub-scale scores of individuals or populations with the reference values for corresponding age-groups and sexes. This can be done both in terms of the healthy comparison group and, where appropriate, with reference to specific diseases. Here the relative deviation of the measured value from the expected value can be quoted.

In a third possible means of interpretation, changes in the patient's clinical condition can be related to changes in his or her self-reported health status based on clinical measurements and quality of life data collected at the same time.

Until the data from a standard sample is available for the KINDL^R questionnaire, the results of a large sample of Hamburg school children (n = 1501) can be used as a preliminary reference for healthy children (Sample 1, cf. Section 1.3). For the following reference values of the sub-scales transformed to a base of 100, the items missing from the short version have been estimated using regression analysis. The scores for the "Disease" module are based on a sample of chronically ill children (Sample 2, cf. Section 1.3). Here again, the scale has been transformed to a range of 0 to 100.

	Children (8 - 12 years old) n = 918				Adolescents (13 - 16 years old) n=583			
	Girls		Boys		Girls		Boys	
	mean	s.d.	mean	s.d.	mean	s.d.	mean	s.d.
KINDL^R – Total Quality of Life Score –100	76,83	8,63	76,67	8,66	70,78	10,01	73,54	8,83
KINDL^R – Physical Well-being–100	74,43	14,19	76,68	13,03	68,24	17,38	77,18	13,07
KINDL^R – Emotional Well-being –100	83,11	11,33	82,89	10,67	79,41	12,89	79,49	11,80
KINDL^R – Self-Esteem –100	66,68	17,83	66,52	18,95	58,14	19,06	63,27	19,34
KINDL^R – Family –100	84,40	12,85	83,58	13,14	75,51	17,68	79,56	17,05
KINDL^R – Friends –100	78,10	13,78	78,21	12,78	78,06	13,47	78,43	11,96
KINDL^R – School –100	74,10	12,29	72,35	12,88	65,19	13,21	63,58	14,04
KINDL^R – Disease –100	60,56	15,25	64,17	13,75	60,10	14,80	64,91	12,90

2 Analysing the KINDL^R Questionnaire

The following instructions for analysing the six sub-scales that make up the KINDL^R questionnaire and for determining the total score, contain general information about the analysis and describe the necessary steps from data entry through to analysis. These steps are the same for all forms – Kiddy, Kid and Kiddo – and for the children's/teenagers' and parents' versions of the KINDL^R questionnaire. Formulas will then be described for summarising the items and for converting the results into sub-scale scores. Finally, the possible ways of dealing with missing data will be dealt with.

As with all standardised instruments, the KINDL^R sub-scales can only be interpreted meaningfully if the contents and the method of analysis are standardised. Changing the content of the questionnaire or the individual steps in its analysis can destroy the reliability and validity of the results. Minor changes can affect the results to a point where comparisons with reference data have to be called into question, and the results of different studies can no longer be compared.

21 General Remarks on the Analysis

The KINDL^R questionnaire is analysed by adding the item responses marked on each sub-scale, with certain items being reversed beforehand. Only sub-scales in which less than 30% of the items are missing can be analysed, whereby mean value replacement is used to deal with such missing values. A computerised analysis program exists for the KINDL^R questionnaire, which carries out both item reversal and the summarisation of the sub-scales and their addition (see Chapter 3, Disc for Data Analysis).

The items and sub-scales of the KINDL^R questionnaire are calculated such that a higher score corresponds to a higher health-related quality of life. Once the data have been entered, analysis of the items and sub-scales is carried out in four steps:

1. Recoding items. This is necessary for 10 (in certain versions for 11) items.
2. Calculating sub-scale scores by adding the items in each sub-scale (raw scores).
3. Combining these to form a total score; and
4. transformation of the sub-scale scores to values between 0 and 100.

These steps may be conducted using the algorithms presented in this Manual, or else using the program on the enclosed floppy disc for the SPSS statistics package.

2.2 Data Entry

The answers to the items in the KINDL^R questionnaire should be entered exactly as coded in the questionnaire, in other words the number that the respondent has ticked, checked, circled or marked in some other way (raw value). In doing so, the response "never" is always assigned the value 1, the alternative response "all the time" the value 5. Occasionally, there may nevertheless be some confusion as to which number to enter. The following guidelines suggest how the most common coding problems should be dealt with:

- If two possible responses are marked for a single question and these responses are adjacent to one another, then one response is chosen according to a random procedure and entered.
- If two possible responses are marked for a single question and these responses are not adjacent to one another, then the item is coded as a missing value.
- If three or more possible responses are marked for a single question, the item is coded as a missing value.

2.3 Recoding Items

The next step following data entry is to recode the responses. Recoding is the process by which item scores are deduced which will then be used in calculating the sub-scale scores. This process consists of several steps:

1. Values that lie outside the valid range are converted into missing values;
2. Scores are reversed; and
3. Missing values are replaced by specific scores which are estimated for each individual.

2.3.1 Responses outside the valid range

Before the final item scores are assigned, all items should be checked to see whether answers occur that lie outside the possible range. Answers outside the valid range are values which are lower than the minimum score of 1 or higher than the maximum score of 5. Scores outside this range are usually due to errors made during data entry, and should – where possible – be replaced by the correct values by referring to the original questionnaire. If the questionnaire is not available, all values that lie outside the permitted range should be recoded as missing values.

2.3.2 Reversing items

10 (in some cases 11) KINDL^R items are worded in such a way that a higher item score implies a poorer health-related quality of life. Reversing the values of these items is necessary in order to ensure that higher scores correspond to a higher health-related quality of life for all the KINDL^R items and sub-scales. Chapter 2.5.1 gives details of which items need to be reversed ★.

2.4 Dealing with Missing Data

In rare cases (1-2% of respondents, or fewer), respondents fail to answer one or several items on a sub-scale. An advantage of sub-scales consisting of several items (like the sub-scales of the KINDL^R) is that a sub-scale score can still be estimated even when some items are missing. The algorithm recommended on the floppy disc replaces each missing value by an estimate made for that specific individual, provided the respondent has answered at least 70% of the items on the sub-scale. This step in the analysis is integrated into the program for data analysis included on the disc.

2.5 Calculation of Sub-Scale Scores

2.5.1 Kid-KINDL^R and Kiddo-KINDL^R

When analysing the KINDL^R questionnaire on the quality of life of children and adolescents in the age range of 8 to 16-year-olds, the following six sub-scale scores can be calculated:

1. Physical Well-being (Items 1★, 2★, 3★, 4)
2. Emotional Well-being (Items 5, 6★, 7★, 8★)
3. Self-esteem (Items 9, 10, 11, 12)
4. Family (Items 13, 14, 15★, 16★)
5. Friends (Items 17, 18, 19, 20★)
6. School (Items 21, 22, *23*, 24★)

With the "School" sub-scale, it should be noted that in the KINDL^R Parents' (8-16 y) and the Kiddo version, Item 23 also has to be reversed.

A Total Score is formed for all the items. Finally, if necessary an additional sub-scale can be calculated using the six question in the "Disease" module:

7. Disease (Items 26★, 27★, 28, 29★, 30★, 31★)

The values are as follows:

1 = never
2 = rarely
3 = sometimes
4 = often
5 = all the time
missing value = "blank"

Important! The items marked with a ★ have to be reversed, i.e. 1=5, 2=4, 3=3, 4=2, 5=1. Response value 5 ("all the time") must be the positive end of the item.

!!! Data entered into the data base must always be in the form of raw data !!!

The sub-scale scores can be quoted in various ways. In the SPSS syntax used on the disc for data analysis, the following quantities are calculated:

- sum score
- sub-scale score (corresponding to the mean of the item scores)
- sub-scale score transformed to a range of 0 to 100

2.5.2 Formulae and examples for calculating sub-scale sum scores

$$\text{Sum score} = \text{Sum of sub-scale items}$$

$$\text{Sub-scale score} = \frac{\text{Sum of sub - scale items}}{\text{Number of sub - scale items}}$$

$$\text{Example: Physical well-being sub-scale score} = \frac{\text{Sum of Items } 1, 2, 3, 4}{4}$$

$$\text{Total score} = \frac{\text{Sum of all items}}{24}$$

$$\text{Sub-scales transformed to 100} = \frac{(\text{Sub - scale score}) - (\text{lowest possible score})}{\text{Possible range of raw score}} \times 100$$

The calculations described here may be found in the SPSS file "kid_kindl_k.sps" (or the corresponding files for other versions) on the disc for data analysis.

2.5.3 Kiddy-KINDL^R

The calculation of sub-scale scores for the parents' version of the Kiddy KINDL^R is essentially the same as described above for the other KINDL^R versions. However the 22 additional items (Items 25 to 46) form a separate sub-scale known as "Kiddy Parents". Here the following items need to be reversed: 25, 28, 31, 34, 36, 38, 39, 41, 44, 45, 46, 48, 49, 51, 52, 53.

In the self-assessment version of the Kiddy interview, only the total score is calculated, and where necessary the additional sub-scale "Disease".

The values for the children's version are as follows:

1 = never

2 = sometimes

3 = very often

2.6 Contact

If you have any questions about the KINDL[R] questionnaire, its short form, the disease-specific modules, translations or the computer questionnaire CAT-Screen, we will be happy to assist you.

You can contact us at the following addresses:

Dr. Ulrike Ravens-Sieberer MPH
Head of the Epidemiological Research Group
"Child and Adolescent Health"
Robert Koch Institute
Stresemannstr. 90
D-10963 BERLIN
Tel: +49-30-4547-3436 (-3434 Office)
Fax: +49-30-4547-3555
E-mail: ravens-siebereru@rki.de

Dr. Ulrike Ravens-Sieberer MPH
Hamburg University
Department for Medical Psychology
Martinistr. 52
D-20246 Hamburg
Tel: +49-40-42803-6206 (-6430 Office)
Fax: +49-40-42803-4940
E-mail: ravens@uke.uni-hamburg.de

Further Reading

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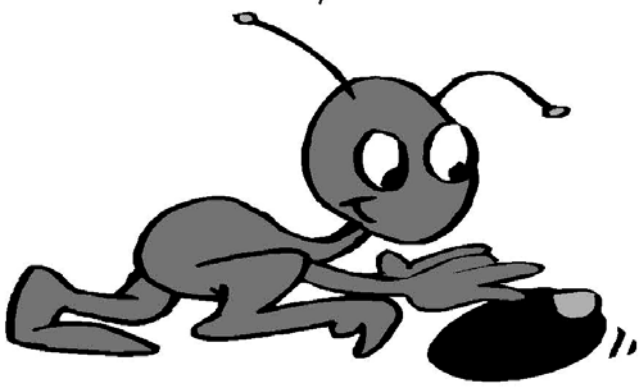
Fragebogen für Kinder

Kiddy-KINDL^R



Hallo,

wir möchten gerne wissen, wie es Dir zur Zeit geht und wie Du Dich fühlst. Dazu haben wir uns einige Fragen ausgedacht und bitten Dich um Deine Antwort.

- ⇨ Ich lese Dir jede Frage vor,
- ⇨ Du überlegst, wie es letzte Woche war und
- ⇨ sage mir dann die Antwort, die für Dich am besten paßt.

Es gibt keine richtigen oder falschen Antworten. Wichtig ist uns Deine Meinung.

Bogen ausgefüllt am:

_____

Tag/Monat/Jahr

PLATZ
FÜR AUFKLEBER
ODER
ID-NUMMER

© Kiddy-Kindl^R / Kinderversion / 4-7 Jahre / Ravens-Sieberer & Bullinger / 1999/ Seite 1

Bitte sage mir zunächst etwas zu Dir

Bist Du ein ❑ Mädchen oder ein ❑ Junge?

Wie alt bist Du? _____ Jahre

Wie viele Geschwister hast Du? ❑ 0 ❑ 1 ❑ 2 ❑ 3 ❑ 4 ❑ 5 ❑ über 5

Gehst Du in den Kindergarten oder in die Vorschule?
❑ Kindergarten ❑ Vorschule ❑ nichts von beidem

Ich lese Dir jetzt ein Beispiel vor:
Wenn Du den Satz hörst: „In der letzten Woche habe ich Lust auf Eisessen gehabt",
kannst **Du** mir sagen, wie häufig das bei **Dir** war?
Es gibt 3 Möglichkeiten zu antworten: **nie, manchmal und ganz oft.**
Also: wie war das bei **Dir**?
Würdest **Du** sagen: In der letzten Woche habe ich...
nie Lust auf Eisessen gehabt,
habe ich **manchmal** Lust auf Eisessen gehabt oder
habe ich **ganz oft** Lust auf Eisessen gehabt

Antwort des Kindes! Wenn der Eindruck besteht, daß das Kind das Antwortschema verstanden hat weiter mit Frage 1, ansonsten Beispiel wiederholen.

Das machst Du sehr gut. Jetzt geht es los.

1. Zuerst möchten ich etwas über Deinen Körper wissen, ...

	In der letzten Woche ...	nie	manchmal	ganz oft
1.	... habe ich mich krank gefühlt			
2.	... hatte ich Kopfweh oder Bauchweh			

2. ... dann etwas darüber, wie Du Dich fühlst ...

	In der letzten Woche ...	nie	manchmal	ganz oft
1.	... habe ich viel gelacht und Spaß gehabt			
2.	... war mir langweilig			

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3. ... und was Du selbst von Dir hältst.

	In der letzten Woche ...	nie	manchmal	ganz oft
1.	... war ich stolz auf mich			
2.	... mochte ich mich selbst leiden			

4. In den nächsten Fragen geht es um Deine Familie ...

	In der letzten Woche ...	nie	manchmal	ganz oft
1.	... habe ich mich gut mit meinen Eltern verstanden			
2.	... habe ich mich zu Hause wohl gefühlt			

5. ... und danach um Freunde.

	In der letzten Woche ...	nie	manchmal	ganz oft
1.	... habe ich mit Freunden gespielt			
2.	... habe ich mich mit meinen Freunden gut verstanden			

6. Nun möchte ich noch etwas über die Vorschule/den Kindergarten wissen.

	In der letzten Woche ...	nie	manchmal	ganz oft
1.	... habe ich die Aufgaben in der Vorschule/im Kindergarten gut geschafft			
2.	... hat mir die Vorschule/der Kindergarten Spaß gemacht			

7. Bist Du gerade im Krankenhaus oder hast Du eine längere Krankheit?

Ja — beantworte bitte die nächsten 6 Fragen

Nein — dann hast Du es jetzt geschafft

	In der letzten Woche ...	nie	manchmal	ganz oft
1.	... hatte ich Angst, meine Krankheit könnte schlimmer werden			
2.	... war ich wegen meiner Krankheit traurig			
3.	... kam ich mit meiner Krankheit gut zurecht			
4.	... behandelten mich meine Eltern wegen der Krankheit wie ein Baby			
5.	... wollte ich, daß keiner etwas von meiner Krankheit merkt			
6.	... habe ich wegen der Krankheit in der Vorschule / dem Kindergarten etwas verpaßt			

VIELEN DANK FÜR DEINE MITARBEIT!

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ID: __ __ __ __ __

Fragebogen zur Lebensqualität von Kindern

4 – 7 Jahre
Elternversion Kindl^{R}

Sehr geehrte Mutter, sehr geehrter Vater,

vielen Dank, daß Sie sich bereit erklärt haben, diesen Bogen zum Wohlbefinden und zur gesundheitsbezogenen Lebensqualität Ihres Kindes auszufüllen.

Bitte beachten Sie beim Beantworten der Fragen folgende Hinweise:

- ⇨ Lesen Sie bitte jede Frage genau durch,
- ⇨ überlegen Sie, wie Ihr Kind sich in der letzten Woche gefühlt hat,
- ⇨ kreuzen Sie die Antwort an, die für Ihr Kind am besten zutrifft.

Ein Beispiel:

In der letzten Woche ...

	nie	selten	manch-mal	oft	immer
... hat mein Kind gut geschlafen.	☐	☐	☐	☒	☐

Mein Kind ist ein: Mädchen ☐ Junge ☐ Alter des Kindes: __ __ Jahre

Sie sind: Mutter ☐ Vater ☐ Sonstiges ☐ _____

Ausfülldatum: __ / __ / __ (Tag / Monat / Jahr)

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1. Körperliches Wohlbefinden

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... hat mein Kind sich krank gefühlt	☐	☐	☐	☐	☐
2. ... hatte mein Kind Kopfschmerzen oder Bauchschmerzen	☐	☐	☐	☐	☐
3. ... war mein Kind müde und schlapp	☐	☐	☐	☐	☐
4. ... hatte mein Kind viel Kraft und Ausdauer	☐	☐	☐	☐	☐

2. Seelisches Wohlbefinden

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... hat mein Kind viel gelacht und Spaß gehabt	☐	☐	☐	☐	☐
2. ... hatte mein Kind zu nichts Lust	☐	☐	☐	☐	☐
3. ... hat mein Kind sich allein gefühlt	☐	☐	☐	☐	☐
4. ... hat mein Kind sich ängstlich oder unsicher gefühlt	☐	☐	☐	☐	☐

3. Selbstwert

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... war mein Kind stolz auf sich	☐	☐	☐	☐	☐
2. ... fühlte mein Kind sich wohl in seiner Haut	☐	☐	☐	☐	☐
3. ... mochte mein Kind sich selbst leiden	☐	☐	☐	☐	☐
4. ... hatte mein Kind viele gute Ideen	☐	☐	☐	☐	☐

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4. Familie

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... hat mein Kind sich gut mit uns als Eltern verstanden	☐	☐	☐	☐	☐
2. ... hat mein Kind sich zu Hause wohl gefühlt	☐	☐	☐	☐	☐
3. ... hatten wir schlimmen Streit zu Hause	☐	☐	☐	☐	☐
4. ... fühlte mein Kind sich durch mich bevormundet	☐	☐	☐	☐	☐

5. Freunde

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... hat mein Kind mit Freunden gespielt	☐	☐	☐	☐	☐
2. ... ist mein Kind bei anderen „gut angekommen“	☐	☐	☐	☐	☐
3. ... hat mein Kind sich gut mit seinen Freunden verstanden	☐	☐	☐	☐	☐
4. ... hatte mein Kind das Gefühl, daß es anders ist als die anderen	☐	☐	☐	☐	☐

6. Vorschule / Kindergarten

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... hat mein Kind die Aufgaben in der Vorschule/ im Kindergarten gut geschafft	☐	☐	☐	☐	☐
2. ... hat meinem Kind die Vorschule/ der Kindergarten Spaß gemacht	☐	☐	☐	☐	☐
3. ... hat mein Kind sich auf die Vorschule/ den Kindergarten gefreut	☐	☐	☐	☐	☐
4. ... hat mein Kind bei kleineren Aufgaben oder Hausaufgaben viele Fehler gemacht	☐	☐	☐	☐	☐

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7. Weitere wichtige Fragen

In der letzten Woche ...		nie	selten	manch-mal	oft	immer
1.	... war mein Kind schlecht gelaunt und quengelig	☐	☐	☐	☐	☐
2.	... hat mein Kind mit Appetit gegessen	☐	☐	☐	☐	☐
3.	... konnte ich geduldig und verständnisvoll mit meinem Kind umgehen	☐	☐	☐	☐	☐
4.	... war mein Kind angestrengt	☐	☐	☐	☐	☐
5.	... konnte mein Kind gut schlafen	☐	☐	☐	☐	☐
6.	... ist mein Kind viel herumgetobt und hat sich bewegt	☐	☐	☐	☐	☐
7.	... hat mein Kind schnell geweint	☐	☐	☐	☐	☐
8.	... war mein Kind fröhlich und gut gelaunt	☐	☐	☐	☐	☐
9.	... konnte sich mein Kind gut konzentrieren und war aufmerksam	☐	☐	☐	☐	☐
10.	... ließ sich mein Kind leicht ablenken und war zerstreut	☐	☐	☐	☐	☐
11.	... war mein Kind gern mit anderen Kindern zusammen	☐	☐	☐	☐	☐
12.	... habe ich mit meinem Kind geschimpft	☐	☐	☐	☐	☐
13.	... habe ich mein Kind gelobt	☐	☐	☐	☐	☐
14.	... hatte mein Kind Schwierigkeiten mit Lehrern, Kindergärtnerinnen oder anderen Betreuungspersonen	☐	☐	☐	☐	☐
15.	... war mein Kind nervös und zappelig	☐	☐	☐	☐	☐
16.	... war mein Kind frisch und munter	☐	☐	☐	☐	☐
17.	... hat mein Kind wegen Schmerzen gejammert	☐	☐	☐	☐	☐
18.	... war mein Kind kontaktfreudig	☐	☐	☐	☐	☐
19.	... klappte alles, was mein Kind anfing	☐	☐	☐	☐	☐
20.	... war mein Kind schnell unzufrieden	☐	☐	☐	☐	☐
21.	... hat mein Kind heftig geweint	☐	☐	☐	☐	☐
22.	... wurde mein Kind leicht wütend	☐	☐	☐	☐	☐

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8. Ist Ihr Kind gerade im Krankenhaus oder hat es eine längere Krankheit?

☐ **Ja**

beantworten Sie bitte die nächsten 6 Fragen

☐ **Nein**

dann ist der Fragebogen nun zu ende

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... hatte mein Kind Angst, die Erkrankung könnte schlimmer werden	☐	☐	☐	☐	☐
2. ... war mein Kind wegen der Erkrankung traurig	☐	☐	☐	☐	☐
3. ... kam mein Kind mit der Erkrankung gut zurecht	☐	☐	☐	☐	☐
4. ... habe ich mein Kind wegen der Erkrankung so behandelt, als ob es jünger wäre	☐	☐	☐	☐	☐
5. ... wollte mein Kind, daß keiner etwas von der Erkrankung merkt	☐	☐	☐	☐	☐
6. ... hat mein Kind wegen der Erkrankung in der Vorschule/ im Kindergarten etwas verpaßt	☐	☐	☐	☐	☐

Vielen Dank für Ihre Mitarbeit

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Fragebogen für Kinder

Kid-KINDL^R

Hallo,

wir möchten gerne wissen, wie es Dir zur Zeit geht. Dazu haben wir uns einige Fragen ausgedacht und bitten Dich um Deine Antwort.

- ⇨ Lies bitte jede Frage durch,
- ⇨ überlege, wie es in der letzten Woche war,
- ⇨ kreuze die Antwort an, die am besten zu Dir paßt.

Es gibt keine richtigen oder falschen Antworten.
Wichtig ist uns <u>Deine</u> Meinung.

<u>Ein Beispiel:</u>	nie	selten	manch-mal	oft	Immer
In der letzten Woche habe ich gerne Musik gehört				X	

Bogen ausgefüllt am:

_____
Tag/Monat/Jahr

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Bitte sage uns zunächst etwas zu Dir. Kreuze an oder trage ein !

Ich bin ein Mädchen Junge

Ich bin _____ Jahre alt

Wieviele Geschwister hast Du? 0 1 2 3 4 5 über 5

Welche Schule besuchst Du? Grundschule Hauptschule Realschule Gesamtschule Gymnasium Sonderschule privater Unterricht

1. Zuerst möchten wir etwas über Deinen Körper wissen, ...

	In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1.	... habe ich mich krank gefühlt					
2.	... hatte ich Kopfschmerzen oder Bauchschmerzen					
3.	... war ich müde und schlapp					
4.	... hatte ich viel Kraft und Ausdauer					

2. ... dann etwas darüber, wie Du Dich fühlst ...

	In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1.	... habe ich viel gelacht und Spaß gehabt					
2.	... war mir langweilig					
3.	... habe ich mich allein gefühlt					
4.	... habe ich Angst gehabt					

3. ... und was Du selbst von Dir hältst.

	In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1.	... war ich stolz auf mich					
2.	... fand ich mich gut					
3.	... mochte ich mich selbst leiden					
4.	... hatte ich viele gute Ideen					

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4. In den nächsten Fragen geht es um Deine Familie ...

	In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1.	... habe ich mich gut mit meinen Eltern verstanden					
2.	... habe ich mich zu Hause wohl gefühlt					
3.	... hatten wir schlimmen Streit zu Hause					
4.	... haben mir meine Eltern Sachen verboten					

5. ... und danach um Freunde.

	In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1.	... habe ich mit Freunden gespielt					
2.	... mochten mich die anderen Kinder					
3.	... habe ich mich mit meinen Freunden gut verstanden					
4.	... hatte ich das Gefühl, daß ich anders bin als die anderen					

6. Nun möchten wir noch etwas über die Schule wissen.

	In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1.	... habe ich die Schulaufgaben gut geschafft					
2.	... hat mir der Unterricht Spaß gemacht					
3.	... habe ich mich auf die nächsten Wochen gefreut					
4.	... habe ich Angst vor schlechten Noten gehabt					

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7. Bist Du gerade im Krankenhaus oder hast Du eine längere Krankheit?

Ja — beantworte bitte die nächsten 6 Fragen

Nein — dann hast Du es jetzt geschafft

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... hatte ich Angst, meine Erkrankung könnte schlimmer werden					
2. ... war ich wegen meiner Erkrankung traurig					
3. ... kam ich mit meiner Erkrankung gut zurecht					
4. ... behandelten mich meine Eltern wegen der Erkrankung wie ein kleines Kind					
5. ... wollte ich, daß keiner etwas von meiner Erkrankung merkt					
6. ... habe ich wegen der Erkrankung in der Schule etwas verpaßt					

VIELEN DANK FÜR DEINE MITARBEIT!

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ID: __ __ __ __ __

Fragebogen zur Lebensqualität von Kindern & Jugendlichen

8-16 Jahre
Elternversion Kindl^{R}

Sehr geehrte Mutter, sehr geehrter Vater,

vielen Dank, daß Sie sich bereit erklärt haben, diesen Bogen zum Wohlbefinden und zur gesundheitsbezogenen Lebensqualität Ihres Kindes auszufüllen.

Bitte beachten Sie beim Beantworten der Fragen folgende Hinweise.

- ⇨ Lesen Sie bitte jede Frage genau durch,
- ⇨ überlegen Sie, wie Ihr Kind sich in der letzten Woche gefühlt hat,
- ⇨ kreuzen Sie die Antwort an, die für Ihr Kind am besten zutrifft.

Ein Beispiel:

In der letzten Woche ...

	nie	selten	manch-mal	oft	immer
... hat mein Kind gut geschlafen	☐	☐	☐	☒	☐

Mein Kind ist ein: Mädchen ☐ Junge ☐ Alter des Kindes: __ __ Jahre

Sie sind: Mutter ☐ Vater ☐ Sonstiges ☐ _____

Ausfülldatum: __ / __ / __ (Tag / Monat / Jahr)

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1. Körperliches Wohlbefinden

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... hat mein Kind sich krank gefühlt	☐	☐	☐	☐	☐
2. ... hatte mein Kind Kopfschmerzen oder Bauchschmerzen	☐	☐	☐	☐	☐
3. ... war mein Kind müde und schlapp	☐	☐	☐	☐	☐
4. ... hatte mein Kind viel Kraft und Ausdauer	☐	☐	☐	☐	☐

2. Seelisches Wohlbefinden

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... hat mein Kind viel gelacht und Spaß gehabt	☐	☐	☐	☐	☐
2. ... hatte mein Kind zu nichts Lust	☐	☐	☐	☐	☐
3. ... hat mein Kind sich allein gefühlt	☐	☐	☐	☐	☐
4. ... hat mein Kind sich ängstlich oder unsicher gefühlt	☐	☐	☐	☐	☐

3. Selbstwert

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... war mein Kind stolz auf sich	☐	☐	☐	☐	☐
2. ... fühlte mein Kind sich wohl in seiner Haut	☐	☐	☐	☐	☐
3. ... mochte mein Kind sich selbst leiden	☐	☐	☐	☐	☐
4. ... hatte mein Kind viele gute Ideen	☐	☐	☐	☐	☐

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4. Familie

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... hat mein Kind sich gut mit uns als Eltern verstanden	☐	☐	☐	☐	☐
2. ... hat mein Kind sich zu Hause wohl gefühlt	☐	☐	☐	☐	☐
3. ... hatten wir schlimmen Streit zu Hause	☐	☐	☐	☐	☐
4. ... fühlte mein Kind sich durch mich bevormundet	☐	☐	☐	☐	☐

5. Freunde

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... hat mein Kind etwas mit Freunden zusammen gemacht	☐	☐	☐	☐	☐
2. ... ist mein Kind bei anderen „gut angekommen“	☐	☐	☐	☐	☐
3. ... hat mein Kind sich gut mit seinen Freunden verstanden	☐	☐	☐	☐	☐
4. ... hatte mein Kind das Gefühl, daß es anders ist als die anderen	☐	☐	☐	☐	☐

6. Schule

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... hat mein Kind die Schulaufgaben gut geschafft	☐	☐	☐	☐	☐
2. ... hat meinem Kind der Unterricht Spaß gemacht	☐	☐	☐	☐	☐
3. ... hat mein Kind sich Sorgen um seine Zukunft gemacht	☐	☐	☐	☐	☐
4. ... hatte mein Kind Angst vor schlechten Noten	☐	☐	☐	☐	☐

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7. Ist Ihr Kind gerade im Krankenhaus oder hat es eine längere Krankheit?

☐ **Ja**

beantworten Sie bitte die nächsten 6 Fragen

☐ **Nein**

dann ist der Fragebogen nun zu ende

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... hatte mein Kind Angst, die Erkrankung könnte schlimmer werden	☐	☐	☐	☐	☐
2. ... war mein Kind wegen der Erkrankung traurig	☐	☐	☐	☐	☐
3. ... kam mein Kind mit der Erkrankung gut zurecht	☐	☐	☐	☐	☐
4. ... habe ich mein Kind wegen der Erkrankung so behandelt, als ob es ein kleines Kind wäre	☐	☐	☐	☐	☐
5. ... wollte mein Kind, daß keiner etwas von der Erkrankung merkt	☐	☐	☐	☐	☐
6. ... hat mein Kind wegen der Erkrankung in der Schule etwas verpaßt	☐	☐	☐	☐	☐

Vielen Dank für Ihre Mitarbeit!

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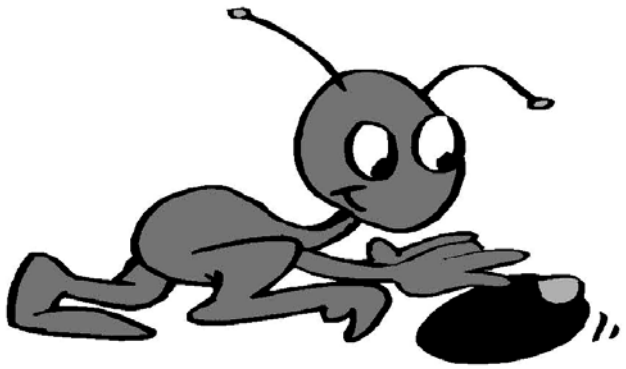
Fragebogen für Jugendliche

Kiddo-KINDL ®



Hallo,
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- ⇨ Lies bitte jede Frage durch,
- ⇨ überlege, wie es in der letzten Woche war,
- ⇨ kreuze die Antwort an, die am besten zu Dir paßt.

Es gibt keine richtigen oder falschen Antworten.
Wichtig ist uns <u>Deine</u> Meinung.

<u>Ein Beispiel:</u>	nie	selten	manch-mal	oft	Immer
In der letzten Woche habe ich gerne Musik gehört				X	

Bogen ausgefüllt am:

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Bitte sage uns zunächst etwas zu Dir. Kreuze an oder trage ein !

Ich bin ein Mädchen Junge

Ich bin _____ Jahre alt

Wie viele Geschwister hast Du? 0 1 2 3 4 5 über 5

Welche Schule besuchst Du? Grundschule Hauptschule Realschule Gesamtschule Gymnasium Sonderschule privater Unterricht

1. Zuerst möchten wir etwas über Deinen Körper wissen, ...

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... habe ich mich krank gefühlt					
2. ... hatte ich Schmerzen					
3. ... war ich müde und erschöpft					
4. ... hatte ich viel Kraft und Ausdauer					

2. ... dann etwas darüber, wie Du Dich fühlst ...

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... habe ich viel gelacht und Spaß gehabt					
2. ... war mir langweilig					
3. ... habe ich mich allein gefühlt					
4. ... habe ich mich ängstlich oder unsicher gefühlt					

3. ... und was Du selbst von Dir hältst.

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... war ich stolz auf mich					
2. ... fühlte ich mich wohl in meiner Haut					
3. ... mochte ich mich selbst leiden					
4. ... hatte ich viele gute Ideen					

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4. In den nächsten Fragen geht es um Deine Familie ...

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... habe ich mich gut mit meinen Eltern verstanden					
2. ... habe ich mich zu Hause wohl gefühlt					
3. ... hatten wir schlimmen Streit zu Hause					
4. ... fühlte ich mich durch meine Eltern eingeschränkt					

5. ... und danach um Freunde.

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... habe ich etwas mit Freunden zusammen gemacht					
2. ... bin ich bei anderen „gut angekommen“					
3. ... habe ich mich mit meinen Freunden gut verstanden					
4. ... hatte ich das Gefühl, daß ich anders bin als die anderen					

6. Nun möchten wir noch etwas über die Schule wissen.

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... habe ich die Aufgaben in der Schule gut geschafft					
2. ... hat mich der Unterricht interessiert					
3. ... habe ich mir Sorgen um meine Zukunft gemacht					
4. ... habe ich Angst vor schlechten Noten gehabt					

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7. Bist Du gerade im Krankenhaus oder hast Du eine längere Krankheit?

Ja — beantworte bitte die nächsten 6 Fragen

Nein — dann hast Du es jetzt geschafft

In der letzten Woche ...	nie	selten	manch-mal	oft	immer
1. ... hatte ich Angst, meine Erkrankung könnte schlimmer werden					
2. ... war ich wegen meiner Erkrankung traurig					
3. ... kam ich mit meiner Erkrankung gut zurecht					
4. ... behandelten mich meine Eltern wegen der Erkrankung wie ein kleines Kind					
5. ... wollte ich, daß keiner etwas von meiner Erkrankung merkt					
6. ... habe ich wegen der Erkrankung in der Schule etwas verpaßt					

VIELEN DANK FÜR DEINE MITARBEIT!

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LONDON HANDICAP SCALE

The London Handicap Scale is a six-item instrument that measures health status in patients with chronic, multiple, or progressive diseases, including evaluation of interventions deployed in their treatment, including rehabilitation. The scale generates a profile of handicaps on six different dimensions (mobility, physical independence, occupation, social integration, orientation, and economic self-sufficiency) and an overall handicap severity score. Each dimension has six levels, arranged in order of increasing disadvantage. Together this information forms a descriptive profile of the individual. The scale is suitable for adults, but was not designed for use with children. The particular issues of chronic disease, multiple pathologies, and the importance of environmental and social factors arise frequently in the elderly, for whom the scale is particularly appropriate.

Abbreviated Name: LHS
Author(s): Harwood RH
Purpose: To assess health status in patients with chronic, multiple, or progressive diseases
Population: Adult
Age Range : 18 and over
Type of Instrument: Quality of life, Disability/Physical Functioning
Mode of Administration:

Rater:	Self-/ Interviewer-administered
Time required:	15-20 minutes
Response Options:	Each dimension (item) has a choice of 6 response options
Scoring:	Global score: Minimum score: 0 / Maximum score: 100 Scores by dimension
Score Direction:	Higher scores show better QoL
Weighting:	Yes

Number of Items: 6
Original Language: English
Existing Translations : Cantonese for Hong-Kong, Czech, Danish, Dutch, Finnish, French, German, Italian, Polish, Slovenian, Spanish, Swedish

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Contact for information and permission to use:

Dr Rowan Harwood
Queen's Medical Centre,
Nottingham NG7 2UH UK
Tel: +44 (0)115 924 9924 ext 42809
Fax: +44 (0)115 970 9947
E-mail: rowan.harwood@mail.qmcuh-tr.trent.nhs.uk

Dimensions covered by the questionnaire :

- Mobility (1 item)
- Physical independence (1 item)
- Occupation (1 item)
- Social integration (1 item)
- Awareness / Orientation (1 item)
- Economic self-sufficiency (1 item)

Key References:

1. Harwood RH, Gompertz P, Ebrahim S. Handicap one year after a stroke: validity of a new scale. J Neurol Neurosurg Psychiatry. 1994 Jul;57(7):825-9.

The aim was to determine the handicap experienced by subjects one year after a stroke, and assess the acceptability, validity, and reliability of a new handicap measurement scale. A cross sectional survey of 141 survivors of a cohort of consecutive hospital admissions with acute stroke was undertaken. The London handicap scale (a new health outcome measurement scale), Barthel index, Nottingham extended activities of daily living scale, Nottingham health profile, Geriatric depression score, and a global life satisfaction scale were used. 94 subjects (67%) responded to a single mailing; 89 (95%) responses were usable. Mean handicap was 0.40 (range 0.06-1.0, SD 0.20) on a scale of 0 (maximum handicap) to 1 (no handicap). All handicap dimensions showed a wide range of problems, with physical independence and occupation particularly affected. Correlations between handicap score and other outcome measures were all in the expected direction and of about the strength expected ($0.36 < r < 0.69$). The reliability coefficient was 0.91, limits of agreement +/- 0.19. The measurements demonstrated substantial handicap one year after a stroke, reflecting considerable unmet rehabilitation needs. The scale proved acceptable to subjects, and the results were consistent with good validity.

2. Harwood RH, Rogers A, Dickinson E, Ebrahim S. Measuring handicap: the London Handicap Scale, a new outcome measure for chronic disease. Qual Health Care. 1994 Mar;3(1):11-6.

Objective:-To develop a handicap measurement scale in a self completion questionnaire format, with scale weights allowing quantification of handicap at an interval level of measurement. Design: Adaptation of the International Classification of Impairments, Disabilities and handicaps into a practical questionnaire incorporating the dimensions of handicap mobility, occupation, physical independence, social integration, orientation, and economic self sufficiency and scale weights derived from interviews with a general population sample, with the technique of conjoint analysis. Setting: Two general practices in different areas of London. Subjects: 240 adults aged 55-74 years randomly selected from the practices, 101 (42%) of whom agreed to be interviewed, and 79 (78%) of whom completed the exercise. Main Measures: Rating of severity of handicap associated with 30 hypothetical health scenarios on a visual analogue scale, from which was derived a matrix of scale weights ("part utilities") relating to different levels of disadvantage on each dimension, with a formula for combining them into an overall handicap score. Severity scores measured directly for five scenarios not used to derive the scale weights were compared with those calculated from the formula to validate the model. Results: The part utilities obtained conformed with the expected hierarchy for each dimension, confirming the validity of the method. The measured severities and those calculated from the formula for the five scenarios used to validate the model agreed closely (Pearson's $r = 0.98$, $p = 0.0009$; Kendall's $tau = 1.00$, $p = 0.007$). Conclusions: This interval level handicap measurement scale will be useful in assessing both specific therapies and health services, in clinical trials, in analyses of cost effectiveness, and in assessments of quality assurance.

THIS IS A TEXTUAL REPRESENTATION OF THE LONDON HANDICAP SCALE AND IS INTENDED FOR REVIEW USE ONLY

This questionnaire is about the way your health affects your everyday life. Please read the instructions for each question and then answer by selecting the sentence which describes you best.
When answering the questions, it may help to think about the things you have done over the last week and compare yourself with someone like you who is in good health.

Getting Around. Think about how you get from one place to another, using any help aids or means of transport that you normally have available. Please select only one.

1. Does your health stop you from getting around?

Not at all: You go everywhere you want to, no matter how far away.
Very Slightly: You go most places you want, but not all.
Quite a lot: You get out of the house, but not far away from it.
Very much: You don't go outside, but you can move around from room to room indoors.
Almost completely: You are confined to a single room, but can move around in it.
Completely: You are confined to bed or chair. You cannot move around at all. There is no one to move you.

Looking After Yourself. Think about things like housework, shopping, looking after money, cooking, laundry, getting dressed, washing, shaving, and using the toilet.

2. Does your health stop you looking after yourself?

Not at all: You do everything to look after yourself.
Very slightly: You need a little help now and again.
Quite a lot: You need help with some tasks (such as heavy housework or shopping), but no more than once a day.
Very much: You do some things for yourself, but you need help more than once a day. You can be left alone safely for a few hours.
Almost completely: You need help to be available all the time. You cannot be left alone safely.
Completely: You need help with everything. You need constant attention, day and night.

Work and Leisure. Think about things like work (paid or not), housework, gardening, sports, hobbies, going out with friends, traveling, reading, looking after children, watching television, and going on holiday.

3. Does your health limit your work or leisure activities?

Not at all: You do everything you want to do.
Very slightly: You do most all the things you want to do.
Quite a lot: You find something to do almost all the time, but cannot do some things for as long as you would like.
Very much: You are unable to do a lot of things, but can find something to do most of the time.
Almost completely: You are unable to do most things, but can find something to do some of the time.
Completely: You sit all day doing nothing. You cannot keep yourself busy or take part in any activities.

Getting on with People. Think about family, friends, and the people you might meet during a normal day.

4. Does your health stop you getting on with people?

Not at all: You get on well with people, see everyone you want to see, and meet new people.
Very slightly: You get on well with people, but your social life is slightly limited.
Quite a lot: You are fine with people you know well, but you feel uncomfortable with strangers.
Very much: You are fine with people you know well, but you have few friends and little contact with neighbours. Dealing with strangers is very hard.
Almost completely: Apart from the people who look after you, you see no-one. You have no friends and no visitors.
Completely: You don't get on with anyone, not even people who look after you.

Awareness of your surroundings. Think about taking in and understanding the world about you, and finding your way around in it.

5. Does your health stop you understanding the world around you?

Not at all: You fully understand the world around you. You see, hear, speak, and think clearly, and you memory is good.
Very slightly: You have problems with hearing, speaking, seeing, or your memory, but these do not stop you doing most things.
Quite a lot: You have problems with hearing, speaking, seeing, or your memory which make life difficult a lot of the time. But, you understand what is going on.
Very much: You have (he/she has) great difficulty understanding what is going on.
Almost completely: He/she is unable to tell where he/she is or what day it is. He/she cannot look after him/herself at all.
Completely: He/she is unconscious, completely unaware of anything going on around him/her.

Affording the things you need. Think about whether health problems have led to any extra expenses, or have caused you to earn less than you would if you were healthy.

6. Are you able to afford the things you need?

Yes, easily: You can afford everything you need. You have easily enough money to buy modern labour-saving devices, and anything you may need because of ill-health.
Fairly easily: You have just about enough money. It is fairly easy to cope with expenses cause by ill-health.
Just about: You are less well off than other people like you; however, with sacrifices you can get by without help.
Not really: You only have enough money to meet your basic needs. You are dependent on state benefits for any extra expenses you have because of ill health.
No: You are dependent on state benefits, or money from other people or charities. You cannot afford things you need.
Absolutely not: You have no money at all and no state benefits. You are totally dependent on charity for your most basic needs.

MCMASTER HEALTH INDEX QUESTIONNAIRE

The McMaster Health Index Questionnaire (MHIQ) have been developed by Larry W. Chambers. Original instruments have been published in English. The purpose of these instruments are to supplement clinical ratings of health status, with QoL measures based on physical, social and emotional functions. The MHIQ focussed on emotional as well as physical aspects of the illness.

Abbreviated Name: MHIQ
Author(s): Larry W. Chambers
Purpose: To supplement clinical ratings of health status, with QoL measures based on physical, social and emotional functions
Population: Adult & Adolescents (from 15 years old)
Age Range : 15 to 65+
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-administered (Phone/ in-person interview have also been tested)
Time required:	20 minutes for self-administration
Response Options:	Yes/No
Scoring:	Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 59
Original Language: English

Contact for information and permission to use:

Larry W. Chambers PhD, FACE, HonFFPH(UK)
Président/President
Institut de recherche Élisabeth-Bruyère /
Élisabeth Bruyère Research Institute
43, rue Bruyère St.
Ottawa (Ontario) K1N 5C8
Tel/Tél. : (613) 562-4262 extension 4059
Fax/Téléc. : (613) 562-4266
E-Mail: lchamber@scohs.on.ca
Website: www.scohs.on.ca/ebri

Dimensions covered by the questionnaire :

- Physical functions
- Social functions
- Emotional

Key References:

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Method of Scoring the MHIQ Physical Function Index

Physical function items	Item scoring: "Good function response weight of "1""	Item scoring: "Poor function response weight of "0""
Today, are you physically able to run a short distance say 300 feet, if you are in a hurry? (This is about the length of a football field or soccer pitch).	YES	NO, NO ANSWER
Today, are you physically able to take part in any sports (hockey, swimming, bowling, glob, and so forth) or exercise regularly?	YES	NO, NO ANSWER
At present, are you physically able to walk out-of-doors *by yourself* when the weather is good?	YES	NO, NO ANSWER
What is the farthest you can walk?	ONE MILE OR MORE — This combination *SCORES ONE*	LESS THAN A 1 MILE BUT MORE THAN 30 FEET, LESS THAN 30 FEET, BETWEEN ROOMS, WITHIN ROOMS, CAN'T WALK AT ALL
Today, do you (or would you) have any physical difficulty at all with walking, as far as a mile?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with climbing up 2 flights of stairs?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with standing up from, and/or sitting down in a chair?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with dusting and/or light housework?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with cleaning floors?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty travelling by bus whenever necessary?	NO	YES, NO ANSWER
Today, do you have any physical difficulty driving a car?	NO or DO NOT HAVE LICENSE	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty feeding yourself?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty undressing?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with washing (face and hands), shaving (men) and/or combing hair?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with shopping?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with cooking?	NO	YES, NO ANSWER
Do you wear glasses?	YES or NO	YES SOMETIMES
Do you have any trouble reading ordinary newsprint?	and NO, NEVER — *SCORE ONE*	YES ALWAYS, NO ANSWER
Do you have a headache after watching television or reading?	and NO, NEVER	
Do you wear a hearing aid?	YES or NO	YES SOMETIMES YES ALWAYS,
Do you have any trouble hearing in a normal conversation with several other persons?	and NO, NEVER — *SCORE ONE*	NO ANSWER
Do you have trouble hearing the radio or television?	and NO, NEVER	
How would you say your *physical* function is today? (By this we mean the ability to move around, see, hear and so forth)		NO, NO ANSWER

$$\text{PHYSICAL FUNCTION INDEX} = \frac{\text{SUM OF ITEMS ASSIGNED "1"}}{19}$$

Method of Scoring the MHIQ Social Function Index

Social function items	Item scoring: "Good function response weight of "1"	Item scoring: "Poor function response weight of "0"
How would you say your health is today?	VERY GOOD, PRETTY GOOD	NOT TOO GOOD, NO ANSWER
Taking all things together, how would you say things are today?	VERY HAPPY, PRETTY HAPPY	NOT TOO HAPPY, NO ANSWER
In general, how satisfying do you find the way you/re spending your life today?	VERY SATISFYING, PRETTY SATISFYING	NOT TOO SATISFYING, NO ANSWER
What is your occupational status?	WORK FULL-TIME, WORK PART-TIME ON VACATION STUDENT A HOUSEWIFE	RETIRED, ON SICK LEAVE, NO ANSWER
How long has it been since you last had a holiday?	LESS THAN OR EQUAL TO 12 MONTHS	GREATER THAN 12 MONTHS
During the last year, have you gone on welfare (or received monies from unemployment insurance, workmen's compensation, or mother's allowance)?	NO	YES, NO ANSWER
During the last year, have you retired from work?	NO	YES, NO ANSWER
Which of the following describe your usual social and recreational activities? going to a relative's home?	YES	NO, NO ANSWER
Has a relative visited you in the last week?	YES	NO, NO ANSWER
During the last year, have you separated from your spouse?	NO	YES, NO ANSWER
During the last year, have you divorced?	NO	YES, NO ANSWER
During the last year, have you had trouble getting along with friends/relatives?	NO	YES, NO ANSWER
During the last year, have you had some other problem or change in your life?	NO	YES, NO ANSWER
How much time in a one-week period do you usually spend watching television?	NONE, LESS THAN 3 HOURS A WEEK, LESS THAN 1 HOUR PER DAY BUT MORE THAN 3 HOURS A WEEK	TWO HOURS OR MORE PER DAY, LESS THAN TWO HOURS PER DAY BUT MORE THAN ONE HOUR A DAY
Which of the following describe your usual social and recreational activities? going to church?	YES	NO, NO ANSWER
Which of the following describe your usual social and recreational activities? any other activities? (please specify)	YES, SOME ACTIVITIES	NONE, NO ANSWER
Has a friend visited you in the last week?	YES	NO, NO ANSWER
Has a religious group member visited you in the last week?	YES	NO, NO ANSWER
Has a social agency representative visited you in the last week? (for example, welfare, mother's allowance, workmen's compensation board, Victoria Order of Nurses)	NO	YES, NO ANSWER
Have you used your telephone in the last week to call a friend?	YES	NO, NO ANSWER
Have you used your telephone in the last week to call a religious group member?	YES	NO, NO ANSWER
Have you used your telephone in the last week to call a social agency representative? (for example, welfare, mother's allowance, workmen's compensation board, Victoria Order of Nurses)	NO	YES, NO ANSWER
Have you been called in the last week by a social agency representative?	NO	YES, NO ANSWER
Do you have a telephone?	YES	NO, NO ANSWER
How would you say your social functioning is today? (By this we mean working with others, getting along with friends or family)	GOOD, GOOD TO FAIR	FAIR, FAIR TO POOR, NO ANSWER

$$\text{SOCIAL FUNCTION INDE X} = \frac{\text{SUM OF ITEMS ASSIGNED "1"}}{25}$$

Method of Scoring the MHIQ Emotional Function Index

Emotional function items	Item scoring: "Good function response weight of "1"	Item scoring: "Poor function response weight of "0"
I sometimes feel that my life is not very useful.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE, AGREE, NEUTRAL, NO ANSWER
I am a useful person to have around.	STRONGLY AGREE, AGREE	STRONGLY DISAGREE, AGREE, NEUTRAL, NO ANSWER
I am inclined to feel I am a failure.	STRONGLY AGREE, AGREE	STRONGLY AGREE, AGREE, NEUTRAL, NO ANSWER
Many people are unhappy because they do not know what they want out of life.	STRONGLY AGREE, AGREE	STRONGLY AGREE, AGREE, NEUTRAL, NO ANSWER
I am a quick thinker.	STRONGLY AGREE, AGREE	STRONGLY ISAGREE, DISAGREE, NEUTRAL, NO ANSWER
Some people feel that they run their lives pretty much the way they want to and that is the case with me.	STRONGLY AGREE, AGREE	STRONGLY DISAGREE, DISAGREE, NEUTRAL, NO ANSWER
I am usually alert.	STRONGLY AGREE, AGREE	STRONGLY DISAGREE, DISAGREE, NEUTRAL, NO ANSWER
Everyone should have someone in his/her life whose happiness means as much to him/her as his/her own.	STRONGLY AGREE, AGREE	STRONGLY DISAGREE, DISAGREE, NEUTRAL, NO ANSWER
In a society where almost everyone is out for himself/herself, people soon come to distrust each other.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE, AGREE, NEUTRAL, NO ANSWER
There are many people who don't know what to do with their lives.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE, AGREE, NEUTRAL, NO ANSWER
Most people don't realize now much their lives are controlled by plots hatched in a secret by others.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE, AGREE, NEUTRAL, NO ANSWER
People feel affectionate toward me.	STRONGLY AGREE, AGREE	STRONGLY DISAGREE, DISAGREE, NEUTRAL, NO ANSWER
I think most married people lead trapped (frustrated or miserable) lives.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE, AGREE, NEUTRAL, NO ANSWER
Some people feel as if other people push them around a good bit and I feel this way too.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE, AGREE, NEUTRAL, NO ANSWER
I would say I nearly always finish things once I start them.	STRONGLY AGREE, AGREE	STRONGLY DISAGREE, DISAGREE, NEUTRAL, NO ANSWER
When I make plans ahead, I usually get to carry things out the way I expected.	STRONGLY AGREE, AGREE	STRONGLY AGREE, AGREE, NEUTRAL, NO ANSWER
It's hardly fair to bring children into the world the way things look for the future.	STRONGLY DISAGREE, DISAGREE	STRONGLY DISAGREE, DISAGREE, NEUTRAL, NO ANSWER
Nowadays a person has to live pretty much for today and let tomorrow take care of itself	STRONGLY DISAGREE, DISAGREE	STRONGLY DISAGREE, DISAGREE, NEUTRAL, NO ANSWER

Emotional function items	Item scoring: "Good function response weight of "1"	Item scoring: "Poor function response weight of "0"
During the last year, have you separated from your spouse?	NO	YES, NO ANSWER
During the last year, have you divorced?	NO	YES, NO ANSWER
During the last year, have you gone on welfare (or received monies from unemployment insurance, workmen's compensation, or mother's allowance)?	NO	YES, NO ANSWER
During the last year, have you had trouble getting along with friends/relatives?	NO	YES, NO ANSWER
During the last year, have you retired from work?	NO	YES, NO ANSWER
During the last year, have you had some other problem or change in your life?	NO	YES, NO ANSWER
How would you say your emotional functioning is today? (By this we mean your ability to remain in good spirits most of the time, and to be usually happy and satisfied with your life.)	GOOD, GOOD TO FAIR	FAIR, FAIR TO POOR, POOR

$$\text{EMOTIONAL FUNCTION INDEX} = \frac{\text{SUM OF ITEMS ASSIGNED "1"}}{25}$$

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MEDICAL OUTCOMES STUDY (MOS) 12-ITEM SHORT FORM

The SF-12® is a multipurpose short-form (SF) generic measure of health status. It was developed to be a much shorter, yet valid, alternative to the SF-36® for use in large surveys of general and specific populations as well as large longitudinal studies of health outcomes. The 12 items in the SF-12® are a subset of those in the SF-36®; SF-12® includes one or two items from each of the eight health concepts. Thus, the SF-12® measures eight concepts commonly represented in widely used surveys: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality (energy/fatigue), social functioning, role limitations due to emotional problems and mental health (psychological distress and psychological well being). Both standard (4-week) and acute (1-week) recall versions are available.

Abbreviated Name: SF-12
Author(s): John E.Ware Jr.
Purpose: Developed to be a much shorter, yet valid, alternative to the SF-36 for use in large surveys of general and specific populations as well as large longitudinal studies of health oucomes
Population: Adult
Age Range : 14+ years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-administered
Time required:	2 minutes
Response Options:	Likert scale
Scoring:	Scores by dimension - PCS (Physical Component Summary) - MCS (Mental Component Summary)
Score Direction:	Higher scores show better QoL

Number of Items: 12
Original Language: English
Existing Translations :
SF 12 :
Bulgarian, Danish, Dutch, Finnish, French, German, Greek, Hebrew, Italian, Norwegian, Polish, Portuguese, Russian, Serbian, Spanish, Swedish
SF 12 v2:
English, Portuguese, Spanish,

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Contact for information and permission to use:

QualityMetric Inc.,
640 George Washington Highway
Suite 201
Lincoln
RI 02865
Phone:+1(401)334-8800
+1(888) 947-9800
Fax: +1(401) 334-8801
E-mail: info@qmetric.com

The Health Assessment Lab
750 Washington Street
Boston
MA 02111
Phone: +1(617)636-8098
+1(800) 572-9394
Fax: +1(617)636-8077

Dimensions covered by the questionnaire :

- Physical functioning
- Role physical
- Bodily pain
- General health
- Vitality
- Social functioning
- Role emotional
- Mental health

Key References:

1. Ware J Jr, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. Med Care 1996; 34:220-33.

Regression methods were used to select and score 12 items from the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) to reproduce the Physical Component Summary and Mental Component Summary scales in the general US population (n=2,333). The resulting 12-item short-form (SF-12) achieved multiple R squares of 0.911 and 0.918 in predictions of the SF-36 Physical Component Summary and SF-36 Mental Component Summary scores, respectively. Scoring algorithms from the general population used to score 12-item versions of the two components (Physical Components Summary and Mental Component Summary) achieved R squares of 0.905 with the SF-36 Physical Component Summary and 0.938 with SF-36 Mental Component Summary when cross-validated in the Medical Outcomes Study. Test-retest (2-week)correlations of 0.89 and 0.76 were observed for the 12-item Physical Component Summary and the 12-item Mental Component Summary, respectively, in the general US population (n=232). Twenty cross-sectional and longitudinal tests of empirical validity previously published for the 36-item short-form scales and summary measures were replicated for the 12-item Physical Component Summary and the 12-item Mental Component Summary, including comparisons between patient groups known to differ or to change in terms of the presence and seriousness of physical and mental conditions, acute symptoms, age and aging, self-reported 1-year changes in health, and recovery for depression. In 14 validity tests involving physical criteria, relative validity estimates for the 12-item Physical Component Summary ranged from 0.43 to 0.93 (median=0.67) in comparison with the best 36-item short-form scale. Relative validity estimates for the 12-item Mental Component Summary in 6 tests involving mental criteria ranged from 0.60 to 107 (median=0.97) in relation to the best 36-item short-form scale. Average scores for the 2 summary measures, and those for most scales in the 8-scale profile based on the 12-item short-form, closely mirrored those for the 36-item short-form, although standard errors were nearly always larger for the 12-item short-form.

SF-12 HEALTH SURVEY

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Please answer every question by marking one box. If you are unsure about how to answer, please give the best answer you can.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
☐	☐	☐	☐	☐

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
2. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐	☐	☐
3. Climbing **several** flights of stairs	☐	☐	☐

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	YES	NO
4. **Accomplished less** than you would like	☐	☐
5. Were limited in the **kind** of work or other activities	☐	☐

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	YES	NO
6. Accomplished less than you would like	☐	☐
7. Didn't do work or other activities as carefully as usual	☐	☐

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐	☐	☐	☐	☐

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks -

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
9. Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
10. Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
11. Have you felt downhearted and blue?	☐	☐	☐	☐	☐	☐

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

MEDICAL OUTCOMES STUDY (MOS) 36-ITEM SHORT FORM

The SF-36® is a 36-item instrument for measuring health status and outcomes from the patient's point of view. Designed for use in surveys of general and specific populations, health policy evaluations, and clinical practice and research, the survey can be self administered by people 14 years of age or older, or administered by trained interviewers either in person or by telephone. The SF-36® measures the following eight health concepts, which are relevant across age, disease and treatment groups: limitations in physical activities because of health problems; limitations in usual role activities because of physical health problems; bodily pain; general health perceptions; vitality (energy and fatigue); limitations in social activities because of physical or emotional problems; limitations in usual role activities because of emotional problems; and mental health (psychological distress and well-being).

The surveys standardized scoring system yields a profile of eight health scores and two summary measures and a self-evaluated change in health status.

Abbreviated Name: SF-36
Author(s): John E.Ware Jr., Ph.D., Cathy D. Sherbourne, Ph.D., Ron D. Hays, Ph.D., Anita Stewart, Sandy Berry, Barbara Gandek, M.S.
Purpose: To satisfy minimum psychometric standards necessary for group comparisons involving generic health concepts — that is, concepts that are not specific to any age, disease, or treatment group
Population: Adult & Adolescent (age 14 and older)
Age Range : 14 and over
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-administered or Interviewer-administered (by a trained interviewer in person or by telephone). Computerized administration is also available.
Time required:	10 minutes
Response Options:	Likert scale and Yes/No
Scoring:	Scores by dimension - Physical Component Summary (PCS) - Mental Component Summary (MCS)
Score Direction:	Higher scores show better QoL

Number of Items: 36
Original Language: English
Existing Translations :
SF 36 :
Afrikaans, Armenian, Bulgarian, Chinese, Croatian, Czech, Danish, Dutch, Finnish, French, German, Greek, Hebrew, Hungarian, Italian, Japanese, Kiswahili, Korean, Latvian, Lithuanian, Norwegian, Polish, Portuguese, Romanian, Russian, Serbian, Slovak, Slovenian, Spanish, Swedish, Turkish
SF 36 v2 :
English, French, German, Italian, Portuguese, Spanish

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Contact for information and permission to use:

QualityMetric Inc.,
640 George Washington Highway
Suite 201
Lincoln
RI 02865
Phone:+1(401)334-8800
+1(888) 947-9800
Fax: +1(401) 334-8801
E-mail: info@qmetric.com

The Health Assessment Lab
750 Washington Street
Boston
MA 02111
Phone: +1(617)636-8098
+1(800) 572-9394
Fax: +1(617)636-8077

Dimensions covered by the questionnaire :

- Physical functioning
- Role physical
- Bodily pain
- General health
- Vitality
- Social functioning
- Role emotional
- Mental health

Key References:

1. McHorney CA, Ware JE Jr, Lu JF, Sherbourne CD. The MOS 36-item Short-Form Health Survey (SF-36): III. Tests of data quality, scaling assumptions, and reliability across diverse patient groups. Med Care. 1994 Jan;32(1):40-66.

The widespread use of standardized health surveys is predicated on the largely untested assumption that scales constructed from those surveys will satisfy minimum psychometric requirements across diverse population groups. Data from the Medical Outcomes Study (MOS) were used to evaluate data completeness and quality, test scaling assumptions, and estimate internal-consistency reliability for the eight scales constructed from the MOS SF-36 Health Survey. Analyses were conducted among 3,445 patients and were replicated across 24 subgroups differing in sociodemographic characteristics, diagnosis, and disease severity. For each scale, item-completion rates were high across all groups (88% to 95%), but tended to be somewhat lower among the elderly, those with less than a high school education, and those in poverty. On average, surveys were complete enough to compute scales scores for more than 96% of the sample. Across patient groups, all scales passed tests for item-internal consistency (97% passed) and item-discriminant validity (92% passed). Reliability coefficients ranged from a low of 0.65 to a high of 0.94 across scales (median = 0.85) and varied somewhat across patient subgroups. Floor effects were negligible except for the two role disability scales. Noteworthy ceiling effects were observed for both role disability scales and the social functioning scale. These findings support the use of the SF-36 survey across the diverse populations studied and identify population groups in which use of standardized health status measures may or may not be problematic.

2. Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care. 1992 Jun;30(6):473-83.

A 36-item short-form (SF-36) was constructed to survey health status in the Medical Outcomes Study. The SF-36 was designed for use in clinical practice and research, health policy evaluations, and general population surveys. The SF-36 includes one multi-item scale that assesses eight health concepts: 1) limitations in physical activities because of health problems; 2) limitations in social activities because of physical or emotional problems; 3) limitations in usual role activities because of physical health problems; 4) bodily pain; 5) general mental health (psychological distress and well-being); 6) limitations in usual role activities because of emotional problems; 7) vitality (energy and fatigue); and 8) general health perceptions. The survey was constructed for self-administration by persons 14 years of age and older, and for administration by a trained interviewer in person or by telephone. The history of the development of the SF-36, the origin of specific items, and the logic underlying their selection are summarized. The content and features of the SF-36 are compared with the 20-item Medical Outcomes Study short-form.

3. McHorney CA, Ware JE Jr, Raczek AE. The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. Med Care. 1993 Mar;31(3):247-63.

Cross-sectional data from the Medical Outcomes Study (MOS) were analyzed to test the validity of the MOS 36-Item Short-Form Health Survey (SF-36) scales as measures of physical and mental health constructs. Results from traditional psychometric and clinical tests of validity were compared. Principal components analysis was used to test for hypothesized physical and mental health dimensions. For purposes of clinical tests of validity, clinical criteria defined mutually exclusive adult patient groups differing in severity of medical and psychiatric conditions. Scales shown in the components analysis to primarily measure physical health (physical functioning and role limitations-physical) best distinguished groups differing in severity of chronic medical condition and had the most pure physical health interpretation. Scales shown to primarily measure mental health (mental health and role limitations-emotional) best distinguished groups differing in the presence and severity of psychiatric disorders and had the most pure mental health interpretation. The social functioning, vitality, and general health perceptions scales measured both physical and mental health components and, thus, had the most complex interpretation. These results are useful in establishing guidelines for the interpretation of each scale and in documenting the size of differences between clinical groups that should be considered very large.

4. McHorney CA, Ware JE Jr, Lu JF, Sherbourne CD. The MOS 36-item Short-Form Health Survey (SF-36): III. Tests of data quality, scaling assumptions, and reliability across diverse patient groups. Med Care. 1994 Jan;32(1):40-66.

The widespread use of standardized health surveys is predicated on the largely untested assumption that scales constructed from those surveys will satisfy minimum psychometric requirements across diverse population groups. Data from the Medical Outcomes Study (MOS) were used to evaluate data completeness and quality, test scaling assumptions, and estimate internal-consistency reliability for the eight scales constructed from the MOS SF-36 Health Survey. Analyses were conducted among 3,445 patients and were replicated across 24 subgroups differing in sociodemographic characteristics, diagnosis, and disease severity. For each scale, item-completion rates were high across all groups (88% to 95%), but tended to be somewhat lower among the elderly, those with less than a high school education, and those in poverty. On average, surveys were complete enough to compute scales scores for more than 96% of the sample. Across patient groups, all scales passed tests for item-internal consistency (97% passed) and item-discriminant validity (92% passed). Reliability coefficients ranged from a low of 0.65 to a high of 0.94 across scales (median = 0.85) and varied somewhat across patient subgroups. Floor effects were negligible except for the two role disability scales. Noteworthy ceiling effects were observed for both role disability scales and the social functioning scale. These findings support the use of the SF-36 survey across the diverse populations studied and identify population groups in which use of standardized health status measures may or may not be problematic.

The standard SF-36® questionnaire

Your Health and Well-Being

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. *Thank you for completing this survey!*

For each of the following questions, please mark an ☒ in the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very Good	Good	Fair	Poor
☐	☐	☐	☐	☐

2. Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
☐	☐	☐	☐	☐

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
b Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐	☐	☐
c Lifting or carrying groceries	☐	☐	☐
d Climbing several flights of stairs	☐	☐	☐
e Climbing one flight of stairs	☐	☐	☐
f Bending, kneeling, or stooping	☐	☐	☐
g Walking more than a mile	☐	☐	☐
h Walking several blocks	☐	☐	☐
i Walking one block	☐	☐	☐
j Bathing or dressing yourself	☐	☐	☐

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(SF-36 Standard, US Version 1.0)

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
a Cut down on the amount of time you spent on work or other activities	☐	☐
b Accomplished less than you would like	☐	☐
c Were limited in the kind of work or other activities	☐	☐
d Had difficulty performing the work or other activities (for example, it took extra effort)	☐	☐

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
a Cut down on the amount of time you spent on work or other activities	☐	☐
b Accomplished less than you would like	☐	☐
c Did work or other activities less carefully than usual	☐	☐

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
☐	☐	☐	☐	☐

7. How much bodily pain have you had during the past 4 weeks?

None	Very mild	Mild	Moderate	Severe	Very Severe
☐	☐	☐	☐	☐	☐

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8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐	☐	☐	☐	☐

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a Did you feel full of pep?	☐	☐	☐	☐	☐	☐
b Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
c Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
d Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
e Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
f Have you felt downhearted and blue?	☐	☐	☐	☐	☐	☐
g Did you feel worn out?	☐	☐	☐	☐	☐	☐
h Have you been a happy person?	☐	☐	☐	☐	☐	☐
i Did you feel tired?	☐	☐	☐	☐	☐	☐

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

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11. How TRUE or FALSE is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a I seem to get sick a little easier than other people.....	☐	☐	☐	☐	☐
b I am as healthy as anybody I know.....	☐	☐	☐	☐	☐
c I expect my health to get worse	☐	☐	☐	☐	☐
d My health is excellent	☐	☐	☐	☐	☐

Thank you for completing these questions!

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MOS SOCIAL SUPPORT SURVEY

The MOS-Social Support Survey (MOS-SSS) is a self-report scale of perceived availability of people who are helpful or supportive with various aspects of life when the respondent is ill. It was developed as part of the Medical Outcomes Study, a two-year longitudinal study of patients with treatable chronic conditions. The MOS-SSS measures emotional/informational support, tangible support, positive social interaction, and affectionate support.

Abbreviated Name: MOS-SSS
Author(s): Cathy Sherbourne and Anita Stewart
Purpose: To assess dimensions of social support
Population: Adult
Age Range : 18+ years
Type of Instrument: Psychosocial
Mode of Administration:

Rater:	Self-/ Interviewer and telephone administered
Time required:	10-15 minutes
Response Options:	Likert scale
Scoring:	Global score: Minimum score: 0 / Maximum score: 100 Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 19
Original Language: English
Existing Translations : Spanish, French, Swedish

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RAND Health Communications
1700 Main Street
P.O. Box 2138
Santa Monica, CA 90407-2138
Phone: (310) 393-0411, ext. 7775
Website: www.rand.org/health
E-mail: RAND_Health@rand.org

Dimensions covered by the questionnaire :

- Emotional / informational support (8 items)
- Tangible support (4 items)
- Positive interaction (3 items)
- Affection (3 items)
- Overall support index (19 items)

Key References:

1. Sherbourne CD and Stewart AL. The MOS Social Support Survey. Soc Sci Med 1991; 32(6): 705-714.

This paper describes the development and evaluation of a brief, multidimensional, self-administered, social support survey that was developed for patients in the Medical Outcomes Study (MOS), a two-year study of patients with chronic conditions. This survey was designed to be comprehensive in terms of recent thinking about the various dimensions of social support. In addition, it was designed to be distinct from other related measures. We present a summary of the major conceptual issues considered when choosing items for the social support battery, describe the items, and present findings based on data from 2987 patients (ages 18 and older). Multitrait scaling analyses supported the dimensionality of four functional support scales (emotional/informational, tangible, affectionate, and positive social interaction) and the construction of an overall functional social support index. These support measures are distinct from structural measures of social support and from related health measures. They are reliable (all Alphas greater than 0.91), and are fairly stable over time. Selected construct validity hypotheses were supported.

MEDICAL OUTCOMES STUDY - SOCIAL SUPPORT SURVEY

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

CIRCLE ONE NUMBER ON EACH LINE

1 = None of the time

2 = A little of the time

3 = Some of the time

4 = Most of the time

5 = All of the time

1	Someone to help you if you were confined to bed……1	2	3	4	5
2	Someone you can count on to listen to you when you need to talk…… 1	2	3	4	5
3	Someone to give you good advice about a crisis……..1	2	3	4	5
4	Someone to take you to the doctor if you needed it ……1	2	3	4	5
5	Someone who shows you love and affection …….. 1	2	3	4	5
6	Someone to have a good time with ……. 1	2	3	4	5
7	Someone to give you information to help you understand a situation ……. 1	2	3	4	5
8	Someone to confide in or talk to about yourself or your problems ……. 1	2	3	4	5
9	Someone who hugs you …….. 1	2	3	4	5
10	Someone to get together with for relaxation ……1	2	3	4	5
11	Someone to prepare your meals if you were unable to do it yourself …… 1	2	3	4	5
12	Someone whose advice you really want ……..1	2	3	4	5
13	Someone to do things with to help you get your mind off things ……..…… 1	2	3	4	5
14	Someone to help with daily chores if you were sick ……1	2	3	4	5
15	Someone to share your most private worries and fears with …1	2	3	4	5
16	Someone to turn to for suggestions about how to deal with a personal problem …… 1	2	3	4	5
17	Someone to do something enjoyable with ……1	2	3	4	5
18	Someone who understands your problems ……1	2	3	4	5
19	Someone to love and make you feel wanted ……1	2	3	4	5

MOSS KITCHEN ASSESSMENT

The MOSS Kitchen Assessment (MKA) have been developed by Celeste Harridge and Suya Shah. Original instruments have been published in English. The purpose of these instruments are to evaluate the ability to interact with the environment, most basic and most predictive Instrumental Activities of Daily Living Scale.

Abbreviated Name: MKA
Author(s): Celeste Harridge, Surya Shah
Purpose: To evaluate the ability to interact with the environment, most basic and most predictive Instrumental Activities of Daily Living Scale
Population: Adult (Spinal injured, Male)
Age Range : Ages 18-88
Type of Instrument: Disability / physical functioning
Mode of Administration:

Rater:	Proxy-administered
Time required:	For direct observation 45 minutes, If not observed 15 minutes
Response Options:	Likert scale
Scoring:	Global score: Minimum score: 0 / Maximum score: 16
Score Direction:	Lower scores show better QoL

Number of Items: 65
Original Language: English

Contact for information and permission to use:

Dr. Surya Shah BAppsc, MEd, PhD, OTR
College of Allied Health Sciences
The University of tennessee
822 BEALE, suite 345
Memphis, TN 38163 USA
Fax: +1- 901-763-0150
Email: Sushah@utmem.edu
Email: shahsurya@hotmail.com

Dimensions covered by the questionnaire :

This is an instrumental Activities of Daily Living Scale (IADL) meal preparation ability evaluates person's ability to interact with their environment

Key References:

1. Harridge C, Shah S (1996) The Moss Kitchen Assessment revised. New Zealand Journal of Occupational Therapy, 46, 5-9.

Performance in instrumental activities of daily living (IADL), if used in conjunction with self care assessment, is predictive of community functioning post discharge. Meal preparation is the most fundamental of all IADL tasks. Hence it is vital for occupational therapists to objectively assess meal preparation ability. This paper presents completed modifications to the Moss Kitchen Assessment according to the established principles of instrument development. Specific modifications included revision of content, improvement of sensitivity for sharper discrimination of level of performance, revision of general criteria, and development of a numerical rating scale. The revisions involved consultations with expert clinicians, academics, and home economists. The guidelines presented here were finalised following a successful pilot study with 20 patients and. four occupational therapists working in pairs.

2. Harridge C, Shah S (1995) A review of meal preparation assessments as a measure of instrumental activities of daily living. New Zealand Journal of Occupational Therapy, 46, 5-12.

This paper explores the concept of assessment of performance in instrumental activities of daily living for estimating a person's ability to interact competently with their environment. It demonstrates that meal preparation is the most basic and hence the most significant homemaking task when assessing a person's ability to interact with their environment. Independence in meal preparation is predictive of performance in domestic activities which determine community functioning of the elderly. A literature review examining a person's ability to prepare meals revealed that traditionally, occupational therapists have relied on subjective observation and checklists to assess performance. Whilst a variety of partially standardised assessments of meal preparation ability exist, these assessments focus on the ability to perform only single simple meal preparation tasks and lack the scope to detect dysfunction in more complex activities. The need for a hierarchical evaluation of meal preparation ability that considers more complex tasks is discussed.

Moss Kitchen Assessment (MKA)

Key

1 = Unable to perform task item.
2 = Maximum assistance. Physical/verbal assistance required for 70% or more of task item.
3 = Moderate assistance. Physical/verbal assistance required for 30- 70% of task item.
4 = Minimum assistance. Physical/verbal assistance required for 0- 30% of task item.
5 = Independent with or without the use of assistive equipment. No physical or verbal assistance needed.

Levels of Evaluation

I. Cold meal (self serve). Serve and eat independently a sandwich and cold drink.
II. Cold meal, prepare and serve. Prepare a sandwich and cold drink.
III. Hot beverage. Prepare a cup of hot tea, coffee, or chocolate drink.
IV. Convenience food. Heat a precooked dinner in a conventional or microwave oven.
V. Simple hot meal. Prepare and serve a simple hot meal such as spaghetti bolognaise or macaroni and cheese following a simple recipe.
VI. Complex hot meal. Plan, prepare, and serve a hot meal choosing appropriate proportions of meat/meat substitute, vegetables, and carbohydrate (pasta, potato, or rice).

General Criteria

To facilitate the meaningful interpretation of assistance required to perform tasks, the following criteria are suggested in using the key:

Appreciation of hot and cold, insight and judgement, static and dynamic sitting and/or standing balance (in and around kitchen and serving area), hygiene (in relation to food preparation and handling), understanding of nutrition (task six), endurance, compensatory ability for neurological deficits such as visual field neglect, ability to plan and organise task, ability to read, and general awareness of safety issues.

Numerical Rating Scale
There is one error. Numerical Score as per key is misplaced. That is, 1 should be removed from Task Level and aligned with scores giving 1 to 5 numerical scores. At the moment, 2 begins where 1 should and 5 finishes where 4 should be and 5 box is blank.

Task Level	Numerical Score as per Key 1	2	3	4	5
I	0	2	5	8	10
II	0	2	5	8	10
III	0	2	6	10	12
IV	0	4	10	16	20
V	0	4	11	18	22
VI	0	5	13	21	26
Total					100

Task and task item **Score** **Comments**

I Cold meal (self serve)
A) PREPARATION
1. Open fridge door, remove sandwich, and drink.
2. Unwrap sandwich.
3. Eat sandwich.
4. Open drink container (e.g., remove lid of plastic cup).
5. Drink.
B) CLEAN UP
6. Carry tray/plate and cup from table to sink.
7. Wipe up crumbs.
8. Throw out rubbish.
II Cold meal (prepare and serve)
A) PREPAPATION
1. Transfer items from fridge to work area.
2. Open packets/containers.
3. Spread bread.
4. Open screw top jars/ containers.
5. Use a can opener (electric or ordinary – assess this item here even if not essential for the activity).
6. Open carton of milk/fruit juice.
7. Pour and drink cold liquid into cup/glass.
B) CLEAN UP
8. Transfer food stuffs back to fridge.
9. Scrape plates/cups.
10. Turn taps on/off.
11. Throw out rubbish.

III Hot Beverage
A) PREPARATION
1. Remove utensils/foodstuffs from high cupboards.

2. Remove utensils/ingredients from low cupboards.
3. Carry full kettle/jug from sink to bench/stove.
4. One of,
i)Turn on/off dials of electric stove.
ii) Light gas stove, turns dials on/off.
iii) Manipulate plug for electric jug, rum switch on/off.
5. Pour hot liquids from heavy jug/kettle into cup without spilling.
6. Carry beverage from bench to table in order to drink.
B) CLEAN UP
7. Wipe up any spills.
8. Throw out rubbish.

IV Convenience meal
A) PREPARATION
1. Open package.
2. Read directions.
3. Follow directions correctly.
4. Open oven door.
5. Place container in oven.
6. Set oven tinier.
7. Respond to tinier signal.
8. Remove hot meal from oven.
9. Transfer meal from hot container to plate.
10. Carry plate from bench to table.
B) CLEANUP
11. Return crockery and cutlery to sink.
12. Scrap plates.
13. Rinse utensils and stack on side of sink.
14. Throw out rubbish.

V Simple hot meal
A) PREPARATION
1. Turn gas/electric stove onloff (if appropriate, lights gas without difficulty).
2. Carry heavy saucepan of water to stove.
3. Strain and rinse pasta.
4. Stir and mix ingredients.
5. Follow given recipe.
6. Safely tend food on stove top/ in oven.
7. Set table.
B) CLEAN UP (include all clean up items from task V, as well as items 8 -1 5 below).
8. Prepare sink - detergent and hot water, manipulate plug.
9. Manipulate dish cloth.
10. Stack crockery into drainer.
11. Wipe down table, stove, and bench.
12. Wring out dish cloth, pull out plug.
13. Wipe up.
14. Put utensils away.
15. Throw out rubbish.

VI Complex Meal
A) PREPARATION
1. Following guidelines, ingredients are chosen from each of the three food groups to develop nutritionally balanced meal.

2. Peel vegetables.
3. Slice vegetables and meat/meat substitute as needed.
4. Strain vegetables.
5. Set table.

B) CLEAN UP

6. Prepare sink -detergent and hot water, manipulate plug.
7. Manipulate dish cloth.
8. Stack crockery into drainer.
9. Wipe down table, stove, and bench.
10. Wring out dish cloth, pull out plug.
11. Wipe up.
12. Put utensils away.
13. Throw out rubbish.

MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL SCALE

Health Locus of Control (HLC) asesses the degree to which individuals believe that their health is controlled by internal or external factors. Whether a person is internal or external is based on a series of statements. The statements are scored and summed to determine whether the individual has internal or external health beliefs. This is called the unidimensional HLC Scale that was developed by Wallston.

Questioning the idea of locus of control as a unidimensional construct. Dr. Hanna Levenson argued that understanding and prediction could be improved by studying fate and chance expectations separately from external control powerful others. Of the six externally worded items on the original health locus of control scale. Only one ["I can do only what my doctor tells me to do"] was related to the dimension of powerful others externally. Wallston&Wallston saw that new items tapping into this dimension were necessary. According to Dr.Levenson powerful others should not be internal or external and beliefs about people in general should have less predictive power than beliefs about one's own control. Realizing the utility and supporting evidence of the multidimensionality, the Multidimensional Health Locus of Control Scale was developed.

Abbreviated Name: MHLC
Author(s): Kenneth A. Wallston
Purpose: To measure the extent of belief that health is determined by behaviour
Population: Adult
Age Range: 13 and over
Type of Instrument: Psychological
Mode of Administration:

Rater:	Self-administered
Time required:	3 minutes
Response Options:	Likert scale
Scoring:	Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 18
Original Language: English
Existing Translations: Brazilian

Contact for information and permission to use:

Kenneth A. Wallston, Ph.D.
School of Nursing
Vanderbilt University
429-B Godchaux Hall
Nashville, TN 37240-0008 USA
Phone: (615) 343-3317
Fax: (615) 343-3998
E-mail: ken.wallston@vanderbilt.edu

Dimensions covered by the questionnaire :

- Internal (3 items)
- Chance (6 items)
- Powerful Others (6 items)
- Doctors (3 items), in Form C only
- Other people (3 items), in Form C only

Key References:

1. Wallston BS, Wallston KA, Kaplan GD, & Maides SA.The development and validation of the health related locus of control (HLC) scale. Journal of Consulting and Clinical Psychology, 1976; 44, 580-585.

2. Wallston KA, Maides SA, & Wallston BS. Health related information seeking as a function of health related locus of control and health value. Journal of Research in Personality, 1976; 10, 215-222.

Two studies were conducted testing the hypothesis that health-related information seeking is a joint function of a person's locus of control beliefs and the value placed on health. Using a health-related measure of locus of control, internal subjects who valued health highly relative to other terminal values (cf. Rokeach, 1973) chose more pamphlets about the particular health condition, hypertension, than did internal-low health value subjects or externals regardless of their health value. Little evidence was found to support the proposition that subject differentially chose pamphlets according to author characieristics (i.e., male or female, doctors or nurses).

3. Wallston BS, Wallston KA. Locus of control and health: A Review of the literature. Health Education Monographs, 1978; 6, 107-117.

Locus of control, an individual difference construct from social learning theory, has shown some promise in predicting and explaining specific health-related behaviors. Research is reviewed on the utility of the locus of control construct in understanding smoking reduction, birth control utilization, weight loss, information-seeking, adherence to medication regimens, and other health or sick-role behaviors. Implications for health educators are presented.

4. Wallston KA, Wallston BS, & DeVellis R. Development of the multidimensional health locus of control (MHLC) scales. Health Education Monographs,1978; 6, 160-170.

The development of the Multidimensional Health Locus of Control scales is described. Scales have been developed to tap beliefs that the source of reinforcements for health-related behaviors is primarily internal, a matter of chance, or under the control of powerful others. These scales are based on earlier work with a general Health Locus of Control Scale, which, in turn, was developed from Rotter's social learning theory. Equivalent forms of the scales are presented along with initial internal consistency and validity data. Possible means of utilizing these scales are provided.

5. Wallston KA, & Wallston BS. Health locus of control scales. In H. Lefcourt (Ed.) Research with the locus of control construct, Volume 1. New York: Academic Press. 1981
6. Wallston KA, & Wallston BS. Who is responsible for your health: The construct of health locus of control. In G. Sanders & J Suls (Eds.) Social Psychology of Health and Illness. Hillsdale, N.J.: Lawrence Erlbaum & Associates, 1982; 65-95.
7. Paine P, Pasquali L, Paulo Ede S, Bianchi AL, Solha AC. Psychometric properties of the Brazilian Health Locus of Control Scale. Psychol Rep. 1994 Aug;75(1 Pt 1):91-4.

Based on social learning theory, the construct of health locus of control has proven valuable in predicting a wide variety of health-related behaviors. In studying this concept among Brazilians, the psychometric properties of the Multidimensional Health Locus of Control Scale translated into Brazilian Portuguese were investigated in a sample of 280 middle-class persons. Three types of health locus of control were verified, internal, powerful others, and chance. Further refinement of subscales is needed to improve internal consistency reliabilities.

SCORING INSTRUCTIONS FOR THE MHLC SCALES

SUBSCALE	FORM(s)	POSSIBLE RANGE	ITEMS
Internal	A, B, C	6 - 36	1, 6, 8, 12, 13, 17
Chance	A, B, C	6 - 36	2, 4, 9, 11, 15, 16
Powerful Others	A, B	6 - 36	3, 5, 7, 10, 14, 18
Doctors	C	3 - 18	3, 5, 14
Other People	C	3 - 18	7, 10, 18

The score on each subscale is the sum of the values circled for each item on the subscale (i.e., where 1 = "strongly disagree" and 6 = "strongly agree"). No items need to be reversed before summing. All of the subscales are independent of one another. There is no such thing as a "total" MHLC score.

Form A

Instructions: Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer EVERY ITEM and that you circle ONLY ONE number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1=STRONGLY DISAGREE (SD) 2=MODERATELY DISAGREE (MD) 3=SLIGHTLY DISAGREE (D)	4=SLIGHTLY AGREE (A) 5=MODERATELY AGREE (MA) 6=STRONGLY AGREE (SA)

		SD	MD	D	A	MA	SA
1	If I get sick, it is my own behavior which determines how soon I get well again.	1	2	3	4	5	6
2	No matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6
3	Having regular contact with my physician is the best way for me to avoid illness.	1	2	3	4	5	6
4	Most things that affect my health happen to me by accident.	1	2	3	4	5	6
5	Whenever I don't feel well, I should consult a medically trained professional.	1	2	3	4	5	6
6	I am in control of my health.	1	2	3	4	5	6
7	My family has a lot to do with my becoming sick or staying healthy.	1	2	3	4	5	6
8	When I get sick, I am to blame.	1	2	3	4	5	6
9	Luck plays a big part in determining how soon I will recover from an illness.	1	2	3	4	5	6
10	Health professionals control my health.	1	2	3	4	5	6
11	My good health is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my health is what I myself do.	1	2	3	4	5	6
13	If I take care of myself, I can avoid illness.	1	2	3	4	5	6
14	Whenever I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.	1	2	3	4	5	6
15	No matter what I do, I 'm likely to get sick.	1	2	3	4	5	6
16	If it's meant to be, I will stay healthy.	1	2	3	4	5	6
17	If I take the right actions, I can stay healthy.	1	2	3	4	5	6
18	Regarding my health, I can only do what my doctor tells me to do.	1	2	3	4	5	6

Form B

Instructions: Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer EVERY ITEM and that you circle ONLY ONE number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1=STRONGLY DISAGREE (SD) 2=MODERATELY DISAGREE (MD) 3=SLIGHTLY DISAGREE (D)	4=SLIGHTLY AGREE (A) 5=MODERATELY AGREE (MA) 6=STRONGLY AGREE (SA)

		SD	MD	D	A	MA	SA
1	If I become sick, I have the power to make myself well again.	1	2	3	4	5	6
2	Often I feel that no matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6
3	If I see an excellent doctor regularly, I am less likely to have health problems.	1	2	3	4	5	6
4	It seems that my health is greatly influenced by accidental happenings.	1	2	3	4	5	6
5	I can only maintain my health by consulting health professionals.	1	2	3	4	5	6
6	I am directly responsible for my health.	1	2	3	4	5	6
7	Other people play a big part in whether I stay healthy or become sick.	1	2	3	4	5	6
8	Whatever goes wrong with my health is my own fault.	1	2	3	4	5	6
9	When I am sick, I just have to let nature run its course.	1	2	3	4	5	6
10	Health professionals keep me healthy.	1	2	3	4	5	6
11	When I stay healthy, I'm just plain lucky.	1	2	3	4	5	6
12	My physical well-being depends on how well I take care of myself.	1	2	3	4	5	6
13	When I feel ill, I know it is because I have not been taking care of myself properly.	1	2	3	4	5	6
14	The type of care I receive from other people is what is responsible for how well I recover from an illness.	1	2	3	4	5	6
15	Even when I take care of myself, it's easy to get sick.	1	2	3	4	5	6
16	When I become ill, it's a matter of fate.	1	2	3	4	5	6
17	I can pretty much stay healthy by taking good care of myself.	1	2	3	4	5	6
18	Following doctor's orders to the letter is the best way for me to stay healthy.	1	2	3	4	5	6

Form C

Instructions: Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer EVERY ITEM and that you circle ONLY ONE number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1=STRONGLY DISAGREE (SD) 2=MODERATELY DISAGREE (MD) 3=SLIGHTLY DISAGREE (D)	4=SLIGHTLY AGREE (A) 5=MODERATELY AGREE (MA) 6=STRONGLY AGREE (SA)

		SD	MD	D	A	MA	SA
1	If my condition worsens, it is my own behavior which determines how soon I will feel better again.	1	2	3	4	5	6
2	As to my condition, what will be will be.	1	2	3	4	5	6
3	If I see my doctor regularly, I am less likely to have problems with my condition.	1	2	3	4	5	6
4	Most things that affect my condition happen to me by chance.	1	2	3	4	5	6
5	Whenever my condition worsens, I should consult a medically trained professional.	1	2	3	4	5	6
6	I am directly responsible for my condition getting better or worse.	1	2	3	4	5	6
7	Other people play a big role in whether my condition improves, stays the same, or gets worse.	1	2	3	4	5	6
8	Whatever goes wrong with my condition is my own fault.	1	2	3	4	5	6
9	Luck plays a big part in determining how my condition improves.	1	2	3	4	5	6
10	In order for my condition to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
11	Whatever improvement occurs with my condition is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my condition is what I myself do.	1	2	3	4	5	6
13	I deserve the credit when my condition improves and the blame when it gets worse.	1	2	3	4	5	6
14	Following doctor's orders to the letter is the best way to keep my condition from getting any worse.	1	2	3	4	5	6
15	If my condition worsens, it's a matter of fate.	1	2	3	4	5	6
16	If I am lucky, my condition will get better.	1	2	3	4	5	6
17	If my condition takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
18	The type of help I receive from other people determines how soon my condition improves.	1	2	3	4	5	6

MULTIDIMENSIONAL TASK ABILITY PROFILE

The Multidimensional Task Ability Profile (MTAP) was developed based on items from the Spinal Function Sort and the Hand Function Sort. An expert judgment exercise was used to supplement these items in cross-reference to the physical domain of the Functional Assessment Constructs taxonomy and the physical abilities section of the Fleishman Job Analysis taxonomy, which has been adopted in O*NET. The 111 items are composed of a pen and ink drawing accompanied by a short task or activity description, with items and a rating scale identical to the Hand Function Sort. English and Spanish versions are available.

MTAP items are presented by computer, beginning with items with the least physical demand, progressing to items that are more difficult. Audio clips of each task or activity description are automatically presented with each item. The evaluee responds through the use of a mouse, keyboard, or touch screen. Scoring and profiling of the responses is performed by the computer. The weighted scoring strategy from the Spinal Function Sort is used to provide a global score that is linked to the DOT Physical Demand Characteristics strength factor. Individual scale scores are provided in a profile.

The Multidimensional Task Ability Profile is first administered at the same time as the functional capacity evaluation that sets the baseline for treatment. A follow-up MTAP is administered every other week to track progress. At discharge from treatment, the MTAP and selected tests from the functional capacity evaluation are administered. Based on serial testing during treatment, a simple "report card" is presented to the evaluee periodically that provides information about the evaluee's current status and a comparison to previous test scores. The MTAP profile appears to be useful to identify functional assessment constructs that require formal performance testing.

Abbreviated Name: MTAP
Author(s): John Mayer, Vert Mooney, Leonard Matheson, Joe Verna, et al.
Purpose: To assess self-reported global functional ability
Population: Adult
Age Range: 18 and over years
Type of Instrument: Disability/physical functioning
Mode of Administration:

Rater:	Self -administered
Time required:	15 minutes
Response Options:	5-point Likert scale from "Able" to "Unable."
Scoring:	Global score Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 111
Original Language: English
Existing Translations: Spanish

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Contact for information and permission to use:

John Mayer
US Spine & Sport Foundation
3444 Kearny Villa Road, Suite
307, San Diego, California 92123 USA
E-mail: jmayer2@san.rr.com

Key References:

1. Matheson LN, Matheson ML, Grant J. Development of a measure of perceived ability. J Occup Rehabil, 1993;3(1):15-30.

The intra-test and test-retest reliability of the Spinal Function Sort was assessed in a multisite study involving 180 disabled subjects. The results of this study demonstrate the reliability of the instrument across a variety of sites. In addition, this study demonstrated both differences in absolute scores and a pattern of reactivity to the instrument that suggests that perceived functional ability may be affected by the subject's degree of chronicity measured in terms of the time that elapsed between date of injury and datae of testing.

2. Matheson LN, Mooney V, Grant J, Affleck M, Hall H, Melles T, Lichter R, McIntosh G. A test to measure lift capacity of physically impaired adults: Part I. Development and reliability testing. Spine, 1995;20(19):2119-29.

Study Design. Two laboratory studies and one field study evaluated the safety and test-retest reliability of a new test of lift capacity. The first two studies were conducted in a carefully controlled laboratory setting. The first study investigated the safety and intra-rater reliability of the EPIC Lift Capacity test protocol with healthy adult subjects. The second study assessed the safety and inter-rater reliability of the test with disabled subjects. The third study was conducted in the field with 65 evaluators and investigated the safety and intra-rater reliability of the test with healthy adult subjects. Objective. To assess the safety and reliability of a new test of lift capacity. Summary of Background Data. A new test of lift capacity has been developed. Test development occurred within the context of ergonomic standards and guide-lines of the major professional associations and public agencies that govern test development in the United States. Methods. In study no. 1, 26 healthy subjects participated. In study no. 2, 14 disabled subjects participated. In study no. 3, 318 healthy subjects participated. After subjects underwent basic screening and warm-up, the EPIC Lift Capacity test was administered. One to 2 weeks later, the test was administered again. Correlations between the times of testing were calculated. Results. No subjects were injured. Hamstring soreness the next day that resolved without complication was reported by some healthy subjects. None of the disabled subjects reported new symptoms. Conclusion. The safety and reliability of the EPIC Lift Capacity test was adequately demonstrated in a laboratory setting and across multiple field sites with evaluators who have varying types and degrees of professional preparation.

3. Matheson LN, Mooney V, Holmes D, Leggett S, Grant J, Negri S, Holmes B. A test to measure lift capacity of physically impaired adults: Part II. Reactivity in a patient sample. Spine, 1995;20(19):2130-4.

Study Design. Test reactivity is the based on the idea that experience with a test may affect performance on subsequent tests, independent of what the test purports to measure. The reactivity of a test of lift capacity was studied in a single-blind randomized clinical trial was studied in a single-blind randomized clinical trial in which subjects were assigned to one or two groups. One group received lift testing before and after a therapeutic trial, while the other group received lift testing only at the conclusion of the therapeutic trial. Objective. To measure the reactivity of a lift capacity test over the course of treatment. Summary of Background Data. The reactivity of a test is an important criterion by which an outcome measure must be judged. Change in response to treatment is assumed to be independent of changes resulting from the evaluee's experience with the test, although this is rarely addressed. Methods. The EPIC Lift Capacity test was administered to 55 patients with low back pain in a treatment program after they were randomized into a pre-test/post-test and a post-test only group. Additional measures were taken on a pre-test/post-test basis for all subjects. Results. Analyses of variance demonstrated no difference between the randomized groups after treatment. However, the pre-test/post-test group demonstrated significant improvement over the course of treatment. Other measures of outcome were similarly affected. Conclusion. The reactivity of the EPIC Lift Capacity test was negligible over an 8-week treatment regimen that did not include lifting tasks.

4. Gibson L, Strong J. The reliability and validity of a measure of perceived functional capacity for work in chronic back pain. J Occup Rehabil, 1996;6(3):159-75.

Psychosocial factors, including perceived disability and self-efficacy, are important determinants of outcome for individuals with chronic back pain. Consequently, there is a need for an evaluation and consideration of such factors in occupational rehabilitation. This study evaluated the reliability and validity

of a tool, the Spinal Function Sort, as a measure of perceived capacity for work-related tasks with 42 rehabilitation clients with chronic back pain. Results provided support for the internal consistency (Cronbach's alpha of 0.97), test-rest reliability (ICC of 0.89) and construct validity of the Spinal Function Sort as a measure of perceived capacity for work-related tasks in persons with chronic back pain. Measures of similar constructs were significantly correlated with the Spinal Function Sort and were highly predictive of the Spinal Function Sort on multiple regression. Relationships between perceived work capacity and pain intensity and gender are discussed. The need for the consideration of perceived capacity in the evaluation and rehabilitation of persons with chronic back pain is highlighted.

5. Mayer JM, Ralph L, Look M, Erasala GN, Verna JL, Matheson LN, Mooney V. Treating acute low back pain with continuous low-level heat wrap therapy and/or exercise: a randomized controlled trial. The Spine Journal 5 (2005) 395–403

Background Context: Restorative exercise and palliative modalities are frequently used together for the treatment of acute low back pain. However, little is known about the effects of combining these treatments. Purpose: To evaluate the efficacy of combining continuous low-level heat wrap therapy with directional preference-based exercise on the functional ability of patients with acute low back pain. Study Design/Setting: A randomized controlled trial was conducted at three outpatient medical facilities. Patient Sample: One hundred individuals (age 31.2±10.6 years) with low back pain of less than 3 months duration. Outcome Measures: The primary outcome measure was functional ability assessed by the Multidimensional Task Ability Profile questionnaire. Secondary outcomes were disability assessed by the Roland-Morris Disability Questionnaire and pain relief assessed by a 6-point verbal rating scale. Methods: Participants were randomized to one of four groups: Heat wrap therapy alone (heat wrap, n=25); directional preference-based exercise alone (exercise, n=25); combination of heat wrap therapy and exercise (heat+exercise, n=24); or control (booklet, n=26). Treatment was administered for five consecutive days and included four visits to the study center over 1 week. Results: At 2 days after the conclusion of treatment (Day 7), functional improvement for heat+exercise was 84%, 95%, and 175% greater than heat wrap, exercise, and booklet, respectively ($p<.05$). Seventy-two percent of the subjects in the heat+exercise group demonstrated a return to pre-injury function compared with 20%, 20%, and 19% for heat wrap, exercise, and booklet, respectively ($p<.05$). Disability reduction for heat+exercise was 93%, 139%, and 400% greater than heat wrap, exercise, and booklet, respectively ($p<.05$). Pain relief for heat+exercise was 70% and 143% greater than exercise and booklet, respectively ($p<.05$). Conclusions: Combining continuous low-level heat wrap therapy with directional preferencebased exercise during the treatment of acute low back pain significantly improves functional outcomes compared with either intervention alone or control. Either intervention alone tends to be more effective than control.

6. Mayer J, Mooney V, Matheson L, Leggett S, Verna J, Balourdas G, DeFilippo G. Reliability and Validity of a New Computer-Administered Pictorial Activity and Task Sort Journal of Occupational Rehabilitation, Vol. 15, No. 2, June 2005

Development of a new pictorial activity and task sort and examination of its reliability and validity is described. The Multidimensional Task Ability Profile (MTAP) is the latest in a series of measures that use a combination of drawings and task descriptions in a self-report format to assess functional capacity. The MTAP is found to be reliable on a test-retest and split-half basis. The concurrent validity of the MTAP was examined in performance testing of lift capacity. Results demonstrate that the MTAP has good concurrent validity.

Multidimensional Task Ability Profile

The purpose of the Multidimensional Task Ability Profile (MTAP) is to quantify an individual's perception of ability to perform functional tasks in order to establish a baseline measure of functional ability, to document change, and to determine specific functional limitations and impairments. Because the MTAP is centered on functional activities, it maintains focus on function throughout evaluation and treatment, and relates evaluation and treatment to daily life, including home and work.

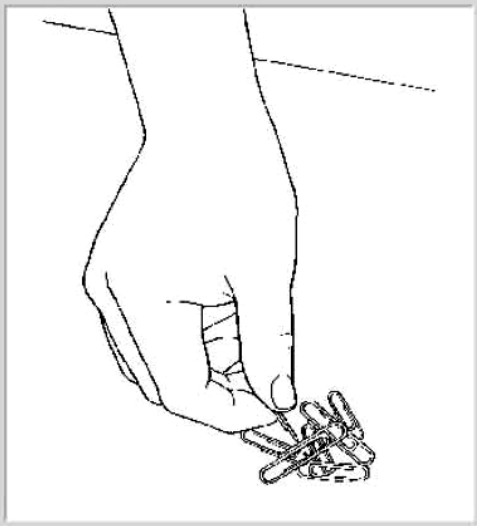
The MTAP is a 111-item computer-administered test, which utilizes captions and drawings that depict progressively demanding functional activities of daily living and work. For each item, the evaluee rates ability to perform the task on a 5-point scale ranging from "Unable" to "Able." Instructions, scoring, and reports are automatically generated. Thus, ***the test is relatively easy to administer and interpret.*** An overall Rating of Perceived Capacity is calculated, which is cross-walked to the U.S. Department of Labor's Physical Demand Characteristic (PDC) of work levels. A Functional Ability Profile is generated summarizing specific functional characteristics such as carrying, lifting, pushing climbing, and reaching. The Functional Ability Profile is defined by the functional assessment taxonomy developed by the U.S. Social Security Administration. Internal consistency of responses is evaluated through "Reliability Check" items on the test.

Research has shown that the MTAP displays high test-retest reliability (r=0.96) and split-half reliability (r=0.98). In addition, the MTAP displays good validity in comparison to the pencil and paper instruments (Spinal Function Sort and Hand Function Sort) from which the MTAP was derived (r = 0.92), and to actual physical testing during functional capacity evaluation (r = 0.87).

Sample MTAP Item

"Carry a full load of laundry up one flight of stairs"

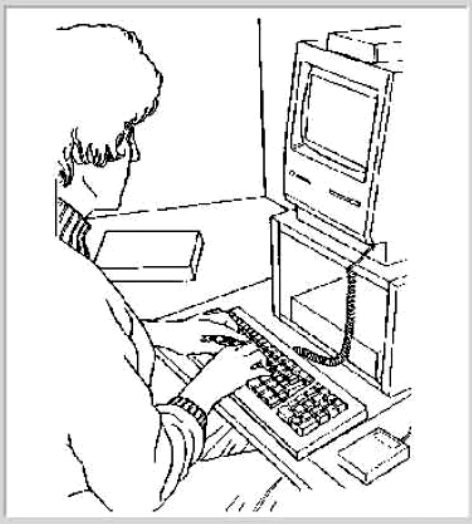
Pick out one large paper clip from a group of small paper clips.



- (●) 1. Able
- ( ) 2. Slightly Restricted
- ( ) 3. Restricted
- ( ) 4. Very Restricted
- ( ) 5. Unable
- ( ) ? Don't Know

Back Next

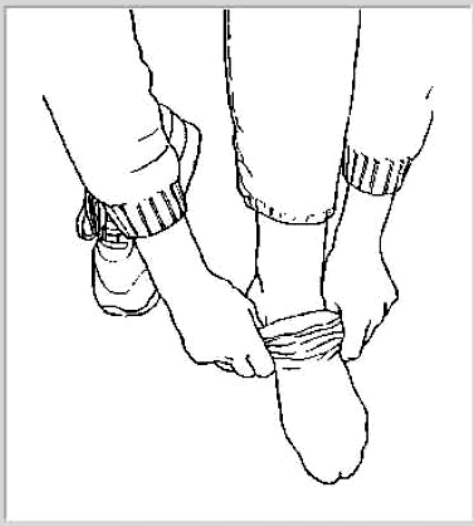
Use a computer keyboard to type a letter.



- ( ) 1. Able
- (●) 2. Slightly Restricted
- ( ) 3. Restricted
- ( ) 4. Very Restricted
- ( ) 5. Unable
- ( ) ? Don't Know

Back Next

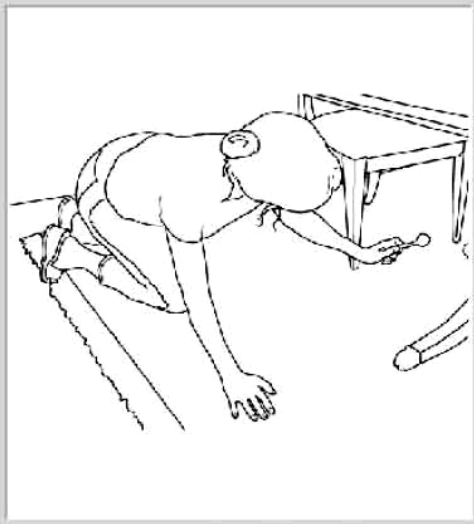
Pull on a pair of socks.



- ○ 1. Able
- ◉ 2. Slightly Restricted
- ○ 3. Restricted
- ○ 4. Very Restricted
- ○ 5. Unable
- ○ ? Don't Know

Back Next

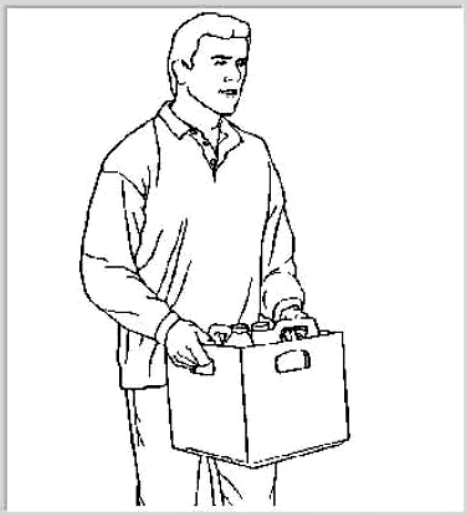
Crawl under a dinner table to retrieve a spoon.



- ○ 1. Able
- ○ 2. Slightly Restricted
- ◉ 3. Restricted
- ○ 4. Very Restricted
- ○ 5. Unable
- ○ ? Don't Know

Back Next

Carry a 50-pound (22.7 kg) crate for 50 feet (15.2 m).



- ○ 1. Able
- ○ 2. Slightly Restricted
- ○ 3. Restricted
- ○ 4. Very Restricted
- ○ 5. Unable
- ○ ? Don't Know

Back Next

Push a full wheelbarrow up a ramp.

- ○ 1. Able
- ○ 2. Slightly Restricted
- ○ 3. Restricted
- ○ 4. Very Restricted
- ○ 5. Unable
- ○ ? Don't Know

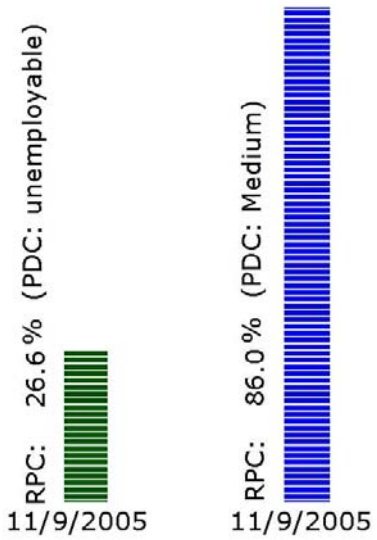
Back Next

PATIENT REPORT CARD
Multidimensional Task Ability Profile
Spine & Sport

example e example November 9, 2005

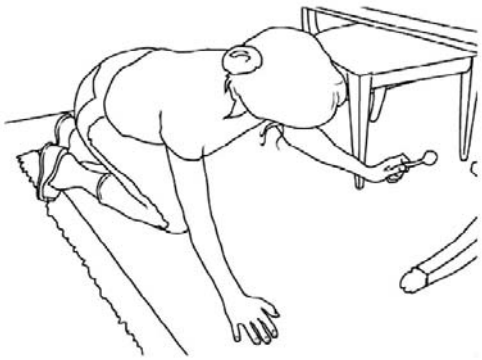
1. Your current Rating of Perceived Capacity (RPC) of 86.0% demonstrates an improvement of 223.7% in functional ability since the test on November 9, 2005. Great Job!

Your current RPC indicates that you are employable for Medium work according to the Physical Demand Characteristic (PDC) levels defined by the U.S. Department of Labor. This is an improvement from your PDC of unemployable on November 9, 2005.



2. Examples of tasks that you currently seem to have difficulty in performing are shown below. Please let us know if we don't seem to be adequately addressing problems such as these, or if you've recently had some problem that has caused you to experience difficulty in these areas. Have a great week!

Sit in an armchair at a theatre for 2 hours.



Crawl under a dinner table to retrieve a spoon.

Spine & Sport
Multidimensional Task Ability Profile
Summary

Patient Name: example e example
Date of Birth: 12/21/1962

Date: 11/9/2005
Referring Physician: Mayer

Reliability Rating on MTAP Test:	Reliable	
Rating of Perceived Capacity (RPC):	382 /444	86.0 %
Physical Demand Characteristics (PDC):	Medium	
Change in RPC & PDC from baseline:	223.7% improvement Baseline Test 11/9/2005	 RPC: 26.6% PDC: Below Sedentary
Change in Functional Ability Profile from baseline:	Overall improvement	

(Please refer to pages 2-5 for details)

Purpose / Overview of the Multidimensional Task Ability Profile (MTAP):
The purpose of the MTAP is to quantify an individual's perception of ability to perform functional tasks in order to establish a baseline measure and to monitor change of functional ability. Because the MTAP is centered on functional activities, it maintains focus on function throughout treatment and relates treatment to daily life, including home and work.

The MTAP is a computer administered test, which utilizes drawings that depict progressively demanding functional activities of daily living and work. For each item, the evaluee rates ability to perform the task on a 5-point scale ranging from "Unable" to "Able". An overall *Rating of Perceived Capacity* (RPC) is established, which corresponds to the U.S. Department of Labor's Physical Demand Characteristic (PDC) of work level. In addition, a Functional Ability Profile is generated summarizing specific functional characteristics such as carrying, lifting, pushing, climbing, and reaching.

Details Page 1

Patient Name: example e example Date: 11/9/2005

(This information is intended to be used in conjunction with the physician's assessment. Please contact us if you have questions.)

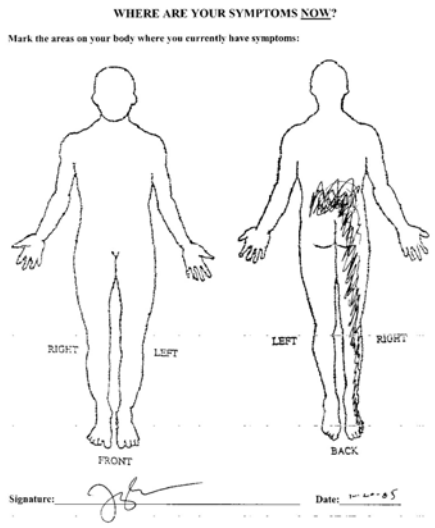
1. Subjective Questions:

	Baseline	Current
Do you think you are in good health?	No	Yes
Do you expect to be at your job within six months?	No	Yes
Do you like your job or usual activity?	No	Yes
Do you have trouble sleeping?	Yes	No

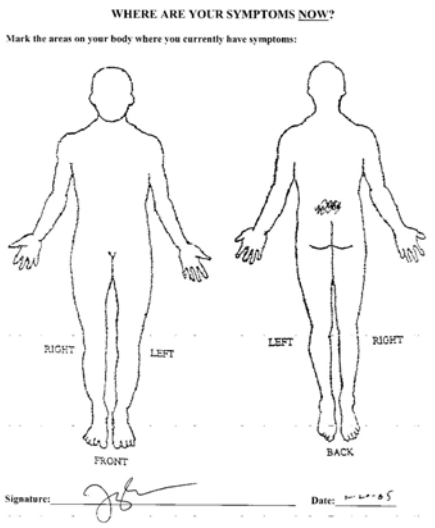
	Baseline	Current
Pain Level:	9.5 (0=No Pain, 10=Worst Imaginable Pain)	1.0
Pain now:	Worse	Better
Characteristics:	Ache, Stabbing, Pins & Needles, Burning	Tired
Usual Severity:	Severe	Slight
Usual Frequency:	Constant	Occasional

Pain Drawings:

Baseline



Current



Details Page 2

Patient Name: example e example Date: 11/9/2005

2. Reliability Rating on MTAP Test: Based on internal consistency of checkpoints within the test, Ms. example's performance on the test was Reliable.

3. Rating of Perceived Capacity (RPC) and Physical Demand Characteristic (PDC) level:

	Baseline %	Current %	Change %
RPC	26.6	86.0	223.7
PDC	Below Sedentary	Medium	

4. Current RPC scores for items specific to each PDC level

Key: 100% able, 75% slightly restricted, 50% restricted, 25% very restricted, 0% unable

	Baseline %	Current %	Change %
Sedentary	68.4	96.1	40.4
Light	34.4	100.0	190.3
Medium	4.2	91.7	2100.0
Heavy	0.0	48.8	?
Very Heavy	0.0	0.0	?

MTAP RPC Scores and Conversion to U.S. Department of Labor's PDC Levels

MTAP RPC	PDC Level	Occasional (0-33% of workday)	Frequent (34-66% of workday)	Constant (67-100% of workday)	Typical Energy Required (METS)
0-144	Below Sedentary				<1.5
145-279	Sedentary	10 lbs.	Negligible	Negligible	1.5-2.1
280-351	Light	10-20 lbs.	10 lbs.	Negligible	2.2-3.5
352-435	Medium	20-50 lbs.	10-20 lbs.	10 lbs.	3.6-6.3
436-443	Heavy	50-100 lbs.	20-50 lbs.	10-20 lbs.	6.4-7.5
444	Very Heavy	> 100 lbs.	> 50 lbs.	> 20 lbs.	> 7.5

Details Page 3

Patient Name: example e example Date: 11/9/2005

5. Functional Ability Profiles:

Key: 100% able, 75% slightly restricted,
50% restricted, 25% very restricted, 0% unable

Functional Characteristic	Baseline%	Current %	Change %
Lower Extremity Range of Motion	6.7	74.3	1003.6
Lower Extremity Stability	7.2	76.3	963.6
Lower Extremity Strength	6.7	74.6	1006.5
Lower Extremity Endurance	7.6	76.2	907.7
Upper Extremity Range of Motion	19.2	81.8	325.9
Upper Extremity Coordination	20.8	83.0	299.1
Upper Extremity Strength	15.5	79.4	410.4
Upper Extremity Endurance	18.5	81.3	340.3
Head and Neck Range of Motion	20.0	82.5	311.8
Trunk Range of Motion	10.5	79.6	659.7
Trunk Stability	10.5	78.7	647.0
Trunk Strength	9.5	77.7	720.3
Trunk Endurance	9.0	76.5	751.6
Hand Strength	13.6	78.3	474.0
Hand Endurance	12.6	79.8	534.1
Hand Range of Motion	26.8	86.9	224.7
Hand Sensitivity	52.9	97.5	84.5
Hand Speed	41.3	98.1	137.2
Hand Coordination	28.3	89.8	218.0
Hand Dexterity	32.2	91.7	184.9
Finger Dexterity	57.3	100.0	74.5
Eye-Hand Coordination	27.5	88.0	219.7
Whole Body Coordination	11.5	79.4	589.2
Visuo-motor coordination	16.6	82.7	398.5
Whole Body Endurance	11.3	78.7	594.1
Balancing	10.2	81.2	698.4
Standing	10.7	81.5	659.4
Sit	16.7	75.0	350.0
Whole Body Positioning	17.0	81.7	381.6
Ambulation	8.5	78.4	817.9
Crawl	0.0	50.0	
Bi-Manual	16.0	81.3	408.7
Manipulating Objects	41.8	94.7	126.5
Reaching	16.3	82.4	404.5
Lifting and Lowering	2.2	69.2	3000.0
Whole Body Pushing and Pulling	6.9	80.6	1060.0
Carrying Objects	4.2	75.0	1700.0
Hand Function Sort*	39.5	89.5	126.5
Spine Function Sort*	10.5	85.5	714.3

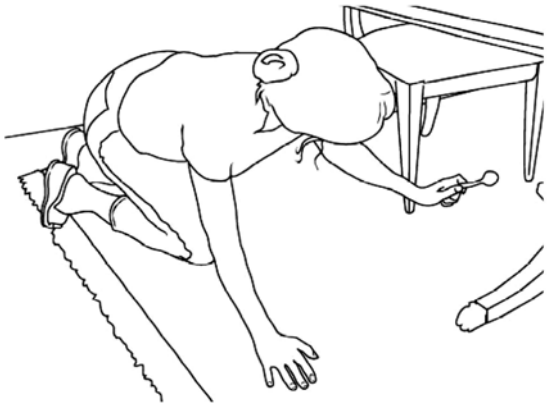
Details Page 4

Patient Name: example e example

Date: 11/9/2005

Examples of tasks for which Ms. example is currently restricted, very restricted or unable to perform are shown below. Treatment will focus on remediating difficulties such as these as she is assisted to improve her overall functional ability.

Sit in an armchair at a theatre for 2 hours.



Crawl under a dinner table to retrieve a spoon.

Carry a 50-pound (22.7 kg) crate for 50 feet (15.2 m).

Lower a 50-pound (22.7 kg) tool box from a bench to the floor.

NOTTINGHAM HEALTH PROFILE

The Nottingham Health Profile contains two parts: Part I contains 38 items that cover 6 domains of experience: pain, physical mobility, sleep, emotional reactions, energy, and social isolation. Part II includes perceived problems in 7 areas of life: paid employment, jobs around the house, personal relationships, social life, sex life, hobbies, and holidays.

Abbreviated Name: NHP
Author(s): S Hunt, J McEwen, SP McKenna
Purpose: To provide a brief indication of a patient's perceived emotional social and physical health problems.
Population: Adult
Age Range : 18 and over
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-administered
Time required:	10 minutes
Response Options:	Yes/No
Scoring:	Global score: Minimum score: 0 / Maximum score: 600 Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 45 (38 in part I and 7 in part II)
Original Language: English
Existing Translations : Arabic, Danish, Dutch, Finnish, French, German, Hungarian, Italian, Japanese, Norwegian, Spanish and Swedish

Contact for information and permission to use:

Galen Research
Southern Hey
Barlow Moor Road
West Didsbury
Manchester
M20 8PW UK
Tel: +44 161 448 1600
Fax: +44 161 446 2544

Dimensions covered by the questionnaire :

- Energy Level (3 items)
- Pain (8 items)
- Emotional reactions (9 items)
- Sleep (5 items)
- Social isolation (5 items)
- Physicial abilities/Mobility (8 items)

Key References:

1. Hunt SM, McEwen J and McKenna, SP (1981) The Nottingham Health Profile User's Manual.
2. Hunt SM, McEwen J, Williams J, Papp E (1981) The NHP: Subjective health status and medical consultations, Social Science and Medicine, 15A, 221-229.

Nottingham Health Profile

Overview:

The Nottingham Health Profile is intended for primary health care, to provide a brief indication of a patient's perceived emotional, social and physical health problems.

Breakdown of questionaire

(1) Part I: 38 questions in 6 subareas, with each question assigned a weighted value; the sum of all weighted values in a given subarea adds up to 100

- energy level (EL): 3
- pain (P): 8
- emotional reaction (ER): 9
- sleep (S): 5
- social isolation (SI): 5
- physical abilities (PA): 8

(2) Part II: 7 life areas affected

Completing questionaire

- each question answered "Yes" or "No"
- important that all questions are answered
- if the patient is not sure whether to say "yes" or "no" to a problem, s/he are instructed to answer the one more true at that time.

Part I

Question	Yes	No	Section	Weight
I'm tired all the time.			EL	39.20
I have pain at night.			P	12.91
Things are getting me down.			ER	10.47
I have unbearable pain.			P	19.74
I take pills to help me sleep.			S	22.37
I've forgotten what it's like to enjoy myself.			ER	9.31
I'm feeling on edge.			ER	7.22
I find it painful to change position.			P	9.99
I feel lonely.			SI	22.01
I can walk about only indoors.			PA	11.54
I find it hard to bend.			PA	10.57
Everything is an effort.			EL	36.80
I'm waking up in the early hours of the morning.			S	12.57
I'm unable to walk at all.			PA	21.30
I'm finding it hard to make contact with people.			SI	19.36

Question	Yes	No	Section	Weight
The days seem to drag.			ER	7.08
I have trouble getting up and down stairs and steps.			PA	10.79
I find it hard to reach for things.			PA	9.30
I'm in pain when I walk.			P	11.22
I lose my temper easily these days.			ER	9.76
I feel there is nobody that I am close to.			SI	20.13
I lie awake for most of the night.			S	27.26
I feel as if I'm losing control.			ER	13.99
I'm in pain when I'm standing.			P	8.96
I find it hard to get dressed by myself.			PA	12.61
I soon run out of energy.			EL	24.00
I find it hard to stand for long (e.g., at the kitchen sink, waiting in a line).			PA	11.20
I'm in constant pain			P	20.86
It takes me a long time to get to sleep.			S	16.10
I feel I am a burden to people.			SI	22.53
Worry is keeping me awake at night.			ER	13.95
I feel that life is not worth living.			ER	16.21
I sleep badly at night.			S	21.70
I'm finding it hard to get along with people.			SI	15.97
I need help to walk about outside (e.g., a walking aid or someone to support me).			PA	12.69
I'm in pain when going up or down stairs.			P	5.83
I wake up feeling depressed.			ER	12.01
I'm in pain when I'm sitting.			P	10.49

Part II

Is your persent state of health causing problems with your:	**Yes**	**No**
Work? (that is, paid employment)		
Looking after the home? (cleaning & cooking, repairs, odd jobs around the home, etc.)		
Social life? (going out, seeing friends, going to the movies, etc.)		
Home life? (that is, relationships with other people in your home)		
Sex life?		
Interests and hobbies? (sports, arts and crafts, do-it-yourself, etc.)		
Vacations? (summer or winter vacations, weekends away, etc.)		

Interpretation

- number of questions in each section affected
- relative level affected, in which the sum of the relative weights are subtracted from 100%, giving values between 0 and 1, with 0 indicating poor and 1 good health

OLDER AMERICANS RESOURCES AND SERVICES MULTIDIMENSIONAL FUNCTIONAL ASSESSMENT QUESTIONNAIRE

The Duke OARS (Older Americans Resources and Services) Program, developed at the Duke Center for the Study of Aging and Human Development, was specifically designed as a means of determining the impact of services and alternative service programs on the functional status of older persons. The resulting brief, valid, and reliable instruments have been used for purposes as varied as individual clinical assessment of personal functional status, surveys of the status of adult populations, assessment of service utilization and service requirements, longitudinal investigations in community, clinic and long-term care settings, and training of service providers.

In order to examine the impact of services on functional state, OARS developed a three-part model: (1) Assessment of individual functional status, in order to group together people of comparable functional status; (2) Disaggregation of services into their generic components, and reaggregation according to actual use (service packages); (3) Use of a transition matrix to study the impact of specific service packages on specific functional states.

The OARS Multidimensional Functional Assessment Questionnaire (OARS-MFAQ) operationalizes the first two parts of this model. The first section of the OARS-MFAQ seeks information on five dimensions of functioning: Social Resources, Economic Resources, Mental Health, Physical Health, and ability to carry out Activities of Daily Living. On each dimension the information obtained is summarized on a 6-point scale where the values range from 1 (level of functioning excellent) to 6 (level of functioning totally impaired). The second section of the OARS-MFAQ inquires about the extent, intensity of utilization, and perceived need for each of 24 non-overlapping, broadly encompassing generic services.

Total administration time for the entire OARS-MFAQ is about 40 minutes. Information is sought in a personal interview with the subject or an informant

Abbreviated Name: OARS MFAQ or OARS
Author(s): Duke University Center for the Study of Aging and Human Development
Purpose: For general multidimensional assessment of the elderly (overall personal functional status and service use)
Population: Geriatrics
Age Range : 18+ years, mainly 45+ years
Type of Instrument: Quality of Life / symptom / functioning
Mode of Administration:

Rater:	Self-, interviewer-, telephone- or proxy-administered
Time required:	40 minutes
Response Options:	Yes/no- Likert scale- relationships, Occupation-open ended, coded later.
Scoring:	Global score Scores by dimension Scores by items
Score Direction:	Higher scores show better QoL (individual items) Lower scores show better QoL (summary score)

Number of Items: 101 (many with subparts)
Original Language: English
Existing Translations : Spanish, Portuguese, Italian, German, Chinese, Afrikaans, Greek, French, Korean

Copyright: 1975, 1988 Duke University Center for the Study of Aging and Human Development

Contact for information and permission to use:

Dr. Harvey Jay Cohen
Director
Center for the Study of Aging and Human Development
Box 3003
Duke University Medical Center
Durham, NC 27710, USA
Fax: +919-684-8569
Email: betty.ray@duke.edu

Dimensions covered by the questionnaire :

- Social resources

(Subject: 9 items, Infomant: 2 items, Interviewer: 2 items)

- Economic resources

(Subject: 15 items, Infomant: 1 items, Interviewer: 3 items)

- Mental health

(Subject: 6 items +2 screens, Infomant: 5 items, Interviewer: 4 items)

- Physical health

(Subject: 16 items, Infomant: 2 items, Interviewer: 1 items)

- ADL

(Subject: 15 items)

- Services

(Subject: 24)

Key References:

1. Fillenbaum GG. Multidimensional functional assessment of older adults: the Duke Older Americans Resources and Services Procedures. Hillsdale, New Jersey: Lawrence Erlbaum Associates. 1988
2. George LK, Fillenbaum GG et al. OARS methodology: a decade of experience in geriatric assessment. J A Geriatr Soc 1985;33:607-615

The Older Americans Resources and Services (OARS) methodology was designed to assess functional capacity in five dimensions (social resources, economic resources, mental health, physical health, and activities of daily living) and to measure use of and need for 24 types of generic services. The OARS questionnaire now has been used in more than 150 research and practice settings. Recent refinements in the OARS methodology include new information about validity and reliability, computerized summary ratings for the five dimensions of functional status, and eleven scales that measure specific aspects of functioning within the five dimensions. This paper describes the conceptual foundation, appropriate uses, psychometric properties, and recent refinements in the OARS methodology. Empirical data from a geriatric clinic population are used for purposes of illustration. The paper presents an assessment of the strengths and limitations of the OARS methodology based on more than a decade of experience. Particular attention is paid to the degree to which the measures of functional status can be related to health service use measures to inform geriatric research and practice.

3. Fillenbaum GG, Smyer MA. The development, validity, and reliability of the OARS multidimensional functional assessment questionnaire. J Gerontol. 1981 Jul;36(4):428-34.

This report outlines the development, validity, and reliability of Part A of the OARS Multidimensional Functional Assessment Questionnaire. Part A permits assessment of individuals' functioning on each of five dimensions (social, economic, mental health, physical health and self-care capacity), the detailed information in each area being summarized on a 6-point rating scale by a rater. Content and consensual validity were ensured by the manner of construction. Information on criterion validity was obtained for all dimensions except social. The criterion used and their associated Kendall's Tau values were: an objective economic scale (.62); ratings based on personal interviews by geropsychiatrists (.60); physician's associates (.82); and physical therapists (.89). For 11 geographically dispersed raters from research and clinic settings, intraclass correlational coefficients, based on 30 subjects, ranged from .66 on physical health to .87 in self-care capacity; 74% of the ratings were in complete agreement, 24% differed by one point.

OARS MULTIDIMENSIONAL FUNCTIONAL ASSESSMENT QUESTIONNAIRE

Subject Number

Subject's Address
Street & Number City State

Date of Interview .....

Time Interview Began .....

Interviewer's Name .....

Relationship of Informant to Subject .....

Place of Interview [BE SPECIFIC.]

Subject's Residence
[SPECIFY HOME OR TYPE OF INSTITUTION.]

OLDER AMERICANS RESOURCES AND SERVICES PROGRAM
OF THE
DUKE UNIVERSITY CENTER FOR THE STUDY OF AGING AND HUMAN DEVELOPMENT
DURHAM, NORTH CAROLINA 27710

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Revised 1988

PRELIMINARY QUESTIONNAIRE
[ASK QUESTIONS 1-10 AND RECORD ALL ANSWERS. (ASK QUESTION 4a ONLY IF SUBJECT HAS NO TELEPHONE.) CHECK CORRECT (+) OR INCORRECT (-) FOR EACH AND RECORD TOTAL NUMBER OF ERRORS BASED ON TEN QUESTIONS.]

1	0	
+	-	
		1. What is the date today? Month Day Year
		2. What day of the week is it? .....
		3. What is the name of this place? .....
		4. What is your telephone number? ..... a. [ASK ONLY IF SUBJECT DOES NOT HAVE A PHONE.] What is your street address? .....
		5. How old are you? .....
		6. When were you born? ..... Month Day Year
		7. Who is the president of the U.S. now? .....
		8. Who was the president just before him? .....
		9. What was your mother's maiden name? .....
		10. Subtract 3 from 20 and keep subtracting 3 from each new number you get, all the way down. ..... [CORRECT ANSWER IS: 17, 14, 11, 8, 5, 2.]

..... Total number of errors.

1. Telephone number [IF SUBJECT IS RELIABLE TRANSFER FROM PRELIMINARY QUESTIONNAIRE; OTHERWISE, OBTAIN FROM INFORMANT OR LOOK ON TELEPHONE.] .....

2. Sex of Subject
   0 Male
   1 Female

3. Race of Subject
   1 White (Caucasian)
   2 Black (Negro)
   3 Oriental
   4 Spanish American (Spanish surname)
   5 American Indian
   6 Other
   - Not answered

4. [GET FROM PRELIMINARY QUESTIONNAIRE IF SUBJECT IS RELIABLE; FROM INFORMANT IF NOT.]
   a. When were you born? .....
      (Month) (Day) (Year)

   b. How old are you? .....

5. How far did you go (have you gone) in school?
   1 0-4 years
   2 5-8 years
   3 High school incomplete
   4 High school completed
   5 Post high school, business or trade school
   6 1-3 years college
   7 4 years college completed
   8 Post graduate college
   - Not answered

SOCIAL RESOURCES

Now I'd like to ask you some questions about your family and friends.

6. Are you single (never married), married, widowed, divorced or separated?
   1 Single (never married)
   2 Married
   3 Widowed
   4 Divorced
   5 Separated
   - Not answered

7. Who lives with you?

[CHECK "YES" OR "NO" FOR EACH OF THE FOLLOWING.]

1 YES	0 NO	
		No one
		Husband or wife
		Children
		Grandchildren
		Parents
		Grandparents
		Brothers and sisters
		Other relatives [Does not include in-laws covered in the .....
		Friends
		Non-related paid* helper [*Includes free room]
		Other [SPECIFY.]

8. How many people do you know well enough to visit with in their homes?
   - 3 Five or more
   - 2 Three or four
   - 1 One or two
   - 0 None
   - - Not answered

9. About how many times did you talk to someone--friends, relatives, or others on the telephone in the past week (either you called them or they called you)? [IF SUBJECT HAS NO PHONE, QUESTION STILL APPLIES.]
   - 3 Once a day or more
   - 2 2-6 times
   - 1 Not at all
   - - Not answered

10. How many times in the past week did you visit with someone, either with people who live here or people who visited you here?
   - 3 Once a day or more
   - 2 2-6 time
   - 1 Once
   - 0 Not at all
   - - Not answered

11. Do you have someone you can trust and confide in?
    1 Yes
    0 No
    - Not answered

12.Do you find yourself feeling lonely quite often, sometimes, or almost never?
    0 Quite often
    1 Sometimes
    2 Almost never
    - Not answered

13.Do you see your relatives and friends as often as you want to, or not?
    1 As often as wants to
    0 Not as often as wants to
    - Not answered

14.Is there someone outside this place who would give you any help at all if you were sick or disabled, for example your husband/wife, a member of your family, or a friend?
    1 Yes
    0 No one willing and able to help
    - Not answered

[IF "YES" ASK a. AND b.]

a.Is there anyone who would take care of you as long as needed, or only for a short time, or only someone who would help you now and then (for example, taking you to the doctor, or fixing lunch occasionally etc.)?

3Someone who would take care of Subject indefinitely (as long as needed)

2Someone who would take care of Subject for a short time (a few weeks to six months)

1Someone who would help the Subject now and then (taking him to the doctor or fixing lunch, etc.)

-Not answered

b. Who is this person?

Name .....

Relationship .....

Code:Spouse = 1, Sibling = 2, Offspring = 3, Grandchild = 4, Other kin = 5, Friend = 6, Other = 7

ECONOMIC RESOURCES

Now I'd like to ask you some questions about your work situation.

15. Are you presently:

[CHECK "YES" OR "NO" FOR EACH OF THE FOLLOWING.]

1 YES	0 NO	
		Employed full-time
		Employed part-time
		Retired
		Retired on disability
		Not employed and seeking work
		Not employed and not seeking work
		Full-time student
		Part-time student

16. What kind of work have you done most of your life?

[CIRCLE THE MOST APPROPRIATE.]

1 Never employed
2 Housewife
3 Other [STATE THE SPECIFIC OCCUPATION IN DETAIL.]
(occupation) .....
- Not answered

17. Does your husband/wife work or did he/she ever work? [QUESTION APPLIES ONLY TO SPOUSE TO WHOM MARRIED THE LONGEST.]
1 Yes
0 No
2 Never married
- Not answered

[IF "YES" ASK a.]

a. What kind of work did or does he/she do?

[STATE THE SPECIFIC OCCUPATION IN DETAIL.] .....

.....
.....

Coding for occupation: Professional = 1, Manager, proprietor = 2, Farmer 50+ acres = 3, Clerical, sales, technical = 4, Skilled, foreman = 5, Semiskilled, operative = 6, Service worker = 7, Unskilled = 8, Farm laborer = 9

18. Where does your income (money) come from (yours and your husband's/wife's)?

[CHECK "YES" OR "NO" FOR EACH OF THE FOLLOWING AND IF "YES" ENTER THE AMOUNT AND CIRCLE "Weekly", "Monthly", OR "Yearly".]

1 YES	0 NO	IF YES HOW MUCH		
			Weekly Monthly Yearly	Earnings from employment (wages, salaries or income from your business)
			Weekly Monthly Yearly	Income from rental, interest from investments, etc. (Include trusts, annuities & payments from insurance policies & interest from savings.)
			Weekly Monthly Yearly	Social Security (Include Social Security disability payments but not SSI.)
			Weekly Monthly Yearly	V.A. benefits such as G.I. Bill, and disability payments
			Weekly Monthly Yearly	Disability payments not covered by Social Security, SSI, or VA. Both government & private & including Workmen's Compensation
			Weekly Monthly Yearly	Unemployment Compensation
			Weekly Monthly Yearly	Retirement pension from job
			Weekly Monthly Yearly	Alimony or child support
			Weekly Monthly Yearly	Scholarships, stipends (Include only the amount beyond tuition.)
			Weekly Monthly Yearly	Regular financial assistance from family members (including regular contributions from employed children)
			Weekly Monthly Yearly	SSI payments (yellow government check)
			Weekly Monthly Yearly	Regular financial aid from private organizations and churches
			Weekly Monthly Yearly	Welfare payments and Aid to Dependent Children
			Weekly Monthly Yearly	Other

[IF COMPLETE INCOME AMOUNTS ARE OBTAINED IN QUESTION 18 SKIP TO QUESTION 19, BUT IF ANY AMOUNTS ARE MISSING ASK a.]

a. How much income do you (and your husband/wife) have a year?

[SHOW ANNUAL INCOME LADDER AND CIRCLE THE LETTER WHICH IDENTIFIES EITHER EARLY OR MONTHLY INCOME CATEGORY.]

CODE		YEARLY	MONTHLY
01	A.	0-$499	(0-$41)
02	B.	$500-$999	($42-$83)
03	C.	$1,000-$1,999	($84-$166)
04	D.	$2,000-$2,999	($167-$249)
05	E.	$3,000-$3,999	($250-$333)
06	F.	$4,000-$4,999	($334-$416)
07	G.	$5,000-$6,999	($417-$583)
08	H.	$7,000-$9,999	($584-$833)
09	I.	$10,000-$14,999	($834-$1,249)
10	J.	$15,000-$19,999	($1,250-$1,666)
11	K.	$20,000-$29,999	($1,667-$2,499)
12	L.	$30,000-$39,999	($2,500-$3,333)
13	M.	$40,000 or more	($3,334 or more)

19. How many people altogether live on this income (that is it provides at least half of their income)? .....

20. Do you own your own home?
    1 Yes
    0 No
    - Not answered

[IF "YES" ASK a. AND b.]

>a. How much is it worth?
    1 Up to $49,000
    2 $ 50,000 - $ 99,000
    3 $ 100,000 - $ 200,000
    4 More than $200,000
    - Not answered

b. Do you own it outright or are you still paying a mortgage?
    1 Own outright
    2 Still paying
    - Not answered

[IF 2 ASK (1.).]

(1.) How much is the monthly payment?
    1 $0-$99
    2 $100-$174
    3 $175-$249
    4 $250-$349
    5 $350-$499
    6 $500-$749
    7 $750 up
    - Not answered

e. Do you have a decent place in which to live?
    1 Yes
    2 No
    - Not answered

>[IF "NO" ASK c. AND d.]

c. Do you (and your husband/wife) pay the total rent for your house (apartment) or do you contribute to the cost, or does someone else own it or pay the rent?
    1 Subject pays total rent
    2 Subject contributes to the cost
    3 Someone else owns it or pays the rent (Subject doesn't contribute)
    - Not answered

[IF 1 OR 2 ASK (1.).]

(1.) How much rent do you pay?
    1 $0-$99 per month
    2 $100-$174
    3 $175-$249
    4 $250-$349
    5 $350-$499
    6 $500-$749
    7 $750 up
    - Not answered

d. Do you live in public housing or receive a rent subsidy?
    0 No, neither
    1 Yes, live in public housing
    2 Yes, receive a rent subsidy
    - Not answered

21. Are your assets and financial resources sufficient to meet emergencies?
    1 Yes
    0 No
    - Not answered

22. Are your expenses so heavy that you cannot meet the payments, or can you barely meet the payments, or are your payments no problem to you?
    1 Subject cannot meet payments
    2 Subject can barely meet payments
    3 Payments are no problem
    - Not answered

23. Is your financial situation such that you feel you need financial assistance or help beyond what you are already getting?
    1 Yes
    0 No
    - Not answered

24. Do you pay for your own food or do you get any regular help at all with costs of food and meals? [INCLUDE FOOD BOUGHT WITH FOOD STAMPS AND MEALS AT NUTRITION SITES.]
    1 Subject pays for food himself
    2 Subject gets help
    - Not answered

    [IF 2 ASK a.]

    a. From where?

    [CHECK "YES" OR "NO" FOR EACH OF THE FOLLOWING.]

1 YES	0 NO	
		Family or friends
		Food stamps
		Prepared food (meals) from an agency or organization program [SPECIFY NUMBER OF MEALS PER WEEK.]

25. Do you feel that you need food stamps?
    1 Yes
    0 No
    - Not answered

26. Are you covered by any kinds of health or medical insurance?
    1 Yes
    0 No
    - Not answered

[IF "YES" ASK a.]

a. What kind?

[CHECK "YES" OR "NO" FOR EACH OF THE FOLLOWING.]

1 YES	0 NO	
		Medicaid
		Medicare Part A only (hospitalization only)
		Medicare Parts A and B (hospitalization and doctors' bills)
		Other Insurance: hospitalization only (Blue Cross or other)
		Other insurance: hospitalization and doctors' bill (Blue Cross and Blue Shield, major medical or other)

27. Please tell me how well you think you are doing financially as compared to other people your age--better, about the same, or worse?
    2 Better
    1 About the same
    0 Worse
    - Not answered

28. How well does the amount of money you have take care of your needs--very well, fairly well, or poorly?
    2 Very well
    1 Fairly well
    0 Poorly
    - Not answered

29. Do you usually have enough to buy those little "extras", that is, those small luxuries?
    1 Yes
    0 No
    - Not answered

30. At the present time do you feel that you will have enough for your
    1 Yes
    0 No
    - Not answered

MENTAL HEALTH

Next, I'd like to ask you some questions about how you feel about life.

31. How often would you say you worry about things--very often, fairly .....
    0 Very often
    1 Fairly often
    2 Hardly ever
    - Not answered

32. In general, do you find life exciting, pretty routine, or dull?
    2 Exciting
    1 Pretty routine
    0 Dull
    - Not answered

33. Taking everything into consideration how would you describe your satisfaction with life in general at the present time--good, fair, or poor?
    2 Good
    1 Fair
    0 Poor
    - Not answered

34. Please answer the following questions "Yes" or "No" as they apply to you now. There are no right or wrong answers, only what best applies to you. Occasionally a question may not seem to apply to you, but please answer either "Yes" or "No", whichever is more nearly correct for you.

[CIRCLE "YES" OR "NO" FOR EACH.]

(1) Do you wake up fresh and rested most mornings?.....yes NO

(2) Is your daily life full of things that keep you interested? .....yes NO

(3) Have you, at times, very much wanted to leave home?.....YES no

(4) Does it seem that no one understands you? .....YES no

(5) Have you had periods of days, weeks, or months when you couldn't take care of things because you couldn't "get going"? .....YES no

(6) Is your sleep fitful and disturbed? .....YES no

(7) Are you happy most of the time? .....yes NO

(8) Are you being plotted against?.....YES no

(9) Do you feel useless at times? .....YES no

(10) During the past few years, have you been well most of the time?.....yes NO

(11) Do you feel weak all over much of the time? .....YES no

(12) Are you troubled by headaches? .....YES no

(13) Have you had difficulty in keeping your balance in walking?.....YES no

(14) Are you troubled by your heart pounding and by a shortness of breath? .....YES no

(15) Even when you are with people, do you feel lonely much of the time?.....YES no

Sum of Responses in Capital letters .....

35. How would you rate your mental or emotional health at the present time -- excellent, good, fair, or poor?
    - 3 Excellent
    - 2 Good
    - 1 Fair
    - 0 Poor
    - - Not answered

36. Is your mental or emotional health now better, about the same, or worse than it was five years ago?
    - 2 Better
    - 1 About the same
    - 0 Worse
    - - Not answered

PHYSICAL HEALTH

Let's talk about your health now.

37. About how many times have you seen a doctor during the past six months other than as an inpatient in a hospital? [EXCLUDE PSYCHIATRISTS.]

    ..... Times

38. During the past six months how many days were you so sick that you were unable to carry on your usual activities--such as going to work or working around the house?
    - 0 None
    - 1 A week or less
    - 2 More than a week but less than one month
    - 3 1-3 months
    - 4 4-6 months
    - - Not answered

39. How many days in the past six months were you in a hospital for physical health problems?

    ..... Days

40. How many days in the past six months were you in a nursing home, or rehabilitation center for physical health problems?

    ..... Days

41. Do you feel that you need medical care or treatment beyond what you are receiving at this time?
    - 1 Yes
    - 0 No
    - - Not answered

42. I have a list of common prescription medications that people take. Would you please tell me if you've taken any of the following *in the past month*.

[CHECK "YES" OR "NO" FOR EACH MEDICINE.]

1 YES	0 NO	
		Arthritis medication
		Prescription pain killer (other than above)
		High blood pressure medicine
		Pills to make you lose water or salt (water pills)
		Digitalis pills for the heart
		Nitroglycerin for chest pain (tablets or patches)
		Blood thinner medicine (anticoagulants)
		Drugs to improve circulation
		Insulin injections for diabetes
		Pills for diabetes
		Prescription ulcer medicine
		Seizure medications (like Dilantin)
		Thyroid pills
		Cortisone pills or injections
		Antibiotics
		Tranquilizers or nerve medicine
		Prescription sleeping pills (once a week or more)
		Hormones, male or female (including birth control pills)

43. What other prescription drugs have you taken in the past month?

[RECORD THE "others". THEN ENTER THEM IN APPROPRIATE CATEGORIES ABOVE IF POSSIBLE.]

[SPECIFY.].....

.....

.....

44. Do you have any of the following illnesses at the present time?

[CHECK "YES" OR "NO" FOR EACH OF THE FOLLOWING. IF "YES" ASK: "How much does it interfere with your activities, not at all, a little (some), or a great deal?" AND CHECK THE APPROPRIATE BOX.]

[IF "YES", ASK:] How much does it interfere with your activities?

	0	1	2	3	
YES	NO	NOT AT ALL	A LITTLE	A GREAT DEAL	
					Arthritis or rheumatism
					Glaucoma
					Asthma
					Emphysema or chronic bronchitis
					Tuberculosis
					High blood pressure
					Heart trouble
					Circulation trouble in arms or legs
					Diabetes
					Ulcers (of the digestive system)
					Other stomach or intestinal disorders or gall bladder problems
					Liver disease
					Kidney disease
					Other urinary tract disorders (including prostate trouble)
					Cancer or Leukemia
					Anemia
					Effects of stroke
					Parkinson's Disease
					Epilepsy
					Cerebral Palsy
					Multiple Sclerosis
					Muscular Dystrophy
					Effects of Polio
					Thyroid or other glandular disorders
					Skin disorders such as pressure sores, leg ulcers or severe burns
					Speech impediment or impairment

45. Do you have any physical disabilities such as total or partial paralysis, missing or non-functional limbs, or broken bones?
    0 No
    1 Total paralysis
    2 Partial paralysis
    3 Missing or non-functional limbs
    4 Broken bones
    - Not answered

46. How is your eyesight (with glasses or contacts)--excellent, good, fair, poor, or are you totally blind?
    1 Excellent
    2 Good
    3 Fair
    4 Poor
    5 Totally blind
    - Not answered

47. How is your hearing--excellent, good, fair, poor, or are you totally deaf? [WITHOUT HEARING AID.]
    1 Excellent
    2 Good
    3 Fair
    4 Poor
    5 Totally deaf
    - Not answered

48. Do you have any other physical problems or illnesses at the present time that seriously affect your health?
    1 Yes
    0 No
    - Not answered

    [IF "YES" SPECIFY.] .....

    .....

SUPPORTIVE DEVICES AND PROTHESES

49. Do you use any of the following aids all or most of the time?

[CHECK "YES" OR "NO" FOR EACH AID.]

1 YES	0 NO	
		Cane (including tripod-tip cane)
		Walker
		Wheelchair
		Leg brace
		Back brace
		Artificial limb
		Hearing aid
		Colostomy equipment
		Catheter
		Kidney dialysis machine
		Other e.g., dentures [SPECIFY.] .....

50. Do you need any aids (supportive or prosthetic devices) that you currently do not have?

1 Yes
0 No
- Not answered

[IF "YES", ASK a.]

a. What aids do you need? [SPECIFY.]

.....

.....

.....

51. Do you have a problem with your health because of drinking or has your physician advised you to cut down on drinking?
    1 Yes
    0 No
    - Not answered

52. Do you regular participate in any vigorous sports activity such as hiking, jogging, tennis, biking, or swimming?

    1 Yes
    0 No
    - Not answered

53. How would you rate your overall health at the present time--excellent, good, fair, or poor?
    3 Excellent
    2 Good
    1 Fair
    0 Poor
    - Not answered

54. Is your health now better, about the same, or worse than it was five years
    2 Better
    1 About the same
    0 Worse
    - Not answered

55. How much do your health troubles stand in the way of your doing the things you want to do--not at all, a little (some), or a great deal?
    2 Not at all
    1 A little (some)
    0 A great deal
    - Not answered

ACTIVITIES OF DAILY LIVING

Now I'd like to ask you about some of the activities of daily living, things that we all need to do as part of our daily lives. I would like to know if you can do these activities without any help at all, or if you need some help to do them, or if you can't do them at all.

[BE SURE TO READ ALL ANSWER CHOICES IF APPLICABLE IN QUESTIONS 56. THROUGH 69. TO RESPONDENT.]

Instrumental ADL

56. Can you use the telephone...
    - 2 without help, including looking up numbers and dialing;
    - 1 with some help (can answer phone or dial operator in an emergency, but need a special phone or help in getting the number or dialing); or
    - 0 are you completely unable to use the telephone?
    - - Not answered

57. Can you get to places out of walking distance...
    - 2 without help (drive your own car, or travel alone on buses, or taxis);
    - 1 with some help (need someone to help you or go with you when traveling); or
    - 0 are you unable to travel unless emergency arrangements are made for a specialized vehicle like an ambulance?
    - - Not answered

58. Can you go shopping for groceries or clothes [ASSUMING S HAS TRANSPORTATION]...
    - 2 without help (taking care of all shopping needs yourself,assuming you had transportation);
    - 1 with some help (need someone to go with you on all shopping trips); or
    - 0 are you completely unable to do any shopping?
    - - Not answered

59. Can you prepare your own meals...
    - 2 without help (plan and cook full meals yourself);
    - 1 with some help (can prepare some things but unable to cook full meals yourself); or
    - 0 are you completely unable to prepare any meals?
    - - Not answered

60. Can you do your housework...
    - 2 without help (can clean floors, etc.);
    - 1 with some help (can do light housework but need help with heavy work); or
    - 0 are you completely unable to do any housework?
    - - Not answered

61. Can you take your own medicine...
    2 without help (in the right doses at the right time);
    1 with some help (able to take medicine if someone prepares it for you and/or reminds you to take it); or
    0 are you completely unable to take your medicines?
    - Not answered

62. Can you handle your own money...
    2 without help (write checks, pay bills, etc.);
    1 with some help (manage day-to-day buying but need help with managing your checkbook and paying your bills); or
    0 are you completely unable to handle money?
    - Not answered

Physical ADL

63. Can you eat...
    2 without help (able to feed yourself completely);
    1 with some help (need help with cutting, etc.); or
    0 are you completely unable to feed yourself?
    - Not answered

64. Can you dress and undress yourself...
    2 without help (able to pick out clothes, dress and undress yourself);
    1 with some help; or
    0 are you completely unable to dress and undress yourself?
    - Not answered

65. Can you take care of your own appearance, for example combing your hair and (for men) shaving...
    2 without help;
    1 with some help; or
    0 are you completely unable to maintain your appearance yourself?
    - Not answered

66. Can you walk...
    2 without help (except from a cane);
    1 with some help from a person or with the use of a walker, or crutches, etc.; or
    0 are you completely unable to walk?
    - Not answered

67. Can you get in and out of bed...
    2 without any help or aids;
    1 with some help (either from a person or with the aid of some device); or
    0 are you totally dependent on someone else to lift you?
    - Not answered

68. Can you take a bath or shower...
    2 without help;
    1 with some help (need help getting in and out of the tub, or need special attachments on the tub); or
    0 are you completely unable to bathe yourself?
    - Not answered

69. Do you ever have trouble getting to the bathroom on time?
    2 No
    0 Yes
    1 Have a catheter or colostomy
    - Not answered

    [IF "YES" ASK a.]

    a. How often do you wet or soil yourself (either day or night)?
        1 Once or twice a week
        0 Three times a week or more
        - Not answered

70. Is there someone who helps you with such things as shopping, housework, bathing, dressing, and getting around?
    1 Yes
    0 No
    - Not answered

    [IF "YES" ASK a. AND b.]

    a. Who is your major helper?

    Name..... Relationship.....

    b. Who else helps you?

    Name..... Relationship.....

UTILIZATION OF SERVICES

71. Now I want to ask you some questions about the kinds of help you are or have been getting or the kinds of help that you feel you need. We want to know not only about the help you have been getting from agencies or organizations but also what help you have been getting from your family and friends.

TRANSPORTATION

(1) Who provides your transportation when you go shopping, visit friends, go to the doctor, etc.?

[CHECK "YES" OR "NO" FOR EACH.]

1 YES	0 NO	
		Yourself
		Your family
		Your friends
		Use public transportation (bus, taxi, subway, etc.)
		Public agency [SPECIFY.].....
		Other [SPECIFY.] .....

a. On the average how many round trips do you make a week?
   0 None
   1 Less than one a week
   2 One to three a week
   3 4 or more
   - Not answered

b. Do you feel you need transportation more often than it is available to you now for appointments, visiting, social events, etc.?
   1 Yes
   0 No
   - Not answered

SOCIAL/RECREATIONAL SERVICES

(2) In the past six months (since..... [SPECIFY MONTH.]) have you participated in any arts and crafts classes, planned and organized social or recreational programs, or in any group activities. [EXCLUDE EMPLOYMENT-RELATED CLASSES.]
   1 Yes
   0 No
   - Not answered

[IF "NO" SKIP TO c.; IF "YES" ASK a., b., AND c.]

a. About how many times a week did you participate in these activities?
   1 Once a week or less
   2 2-3 times a week
   3 4 times a week or more
   - Not answered

b. Do you still participate in such activities or groups?
   1 Yes
   0 No
   - Not answered

c. Do you feel you need to participate in any planned and organized social or recreational programs or in any group activities or classes?
   1 Yes
   0 No
   - Not answered

EMPLOYMENT SERVICES

(3) Has anyone helped you look for or find a job or counseled you in regard to getting employment in the past six months (since .....[MONTH])?
   1 Yes
   0 No
   - Not answered

[IF "NO" SKIP TO b.; IF "YES" ASK a. AND b.]

a. Who helped you?

1 YES	0 NO	
		Family member
		Friend
		Agency

b. Do you feel you need someone to help you find a job?
   1 Yes
   0 No
   - Not answered

SHELTERED EMPLOYMENT

(4) During the past six months have you worked in a place like a sheltered workshop that employs people with disabilities or special problems?
   1 Yes
   0 No
   - Not answered

[IF "NO" SKIP TO b.; IF "YES" ASK a. AND b.]

a. Do you still work there?
   1 Yes
   0 No
   - Not answered

b. Do you feel you need to work in a sheltered workshop?
   1 Yes
   0 No
   - Not answered

EDUCATIONAL SERVICES, EMPLOYMENT RELATED

(5) In the past six months have you had any occupational training or on the job training to further prepare you for a job or career?
   1 Yes
   0 No
   - Not answered

[IF "NO" SKIP TO c.; IF "YES" ASK a., b., AND c.]

a. Was this full or part-time training?
   1 Full-time
   2 Part-time
   - Not answered

b. Are you still in classes or training?
   1 Yes
   0 No
   - Not answered

c. Do you feel you need educational or on the job training to prepare you for the job?
   1 Yes
   0 No
   - Not answered

REMEDIAL TRAINING

(6) In the past six months have you had any training or instruction in learning basic personal skills, for example how to care for yourself, speech therapy, reality orientation, or training for the blind or physically or mentally handicapped?
[EXCLUDE PHYSICAL THERAPY.]
   1 Yes
   0 No
   - Not answered

[IF "NO" SKIP TO c.; IF "YES" ASK a., b., AND c.]

a. On average about how many training sessions a week did you have over the past six months?
   1 Less than one a week
   2 One a week
   3 Two or more a week
   - Not answered

b. Are you currently receiving this type of training or instruction?
   1 Yes
   0 No
   - Not answered

c. Do you think you need remedial training or instruction in basic personal skills?
   1 Yes
   0 No
   - Not answered

MENTAL HEALTH SERVICES

(7) Have you had any treatment or counseling for personal or family problems, or for nervous or emotional problems in the past six months, that is, since _____ [SPECIFY MONTH.]?
   1 Yes
   0 No
   - Not answered

[IF "NO" SKIP TO d.; IF "YES" ASK a., b., c., AND d.]

a. Were you hospitalized for nervous or emotional problems at any time during this period? (Last six months)
   1 Yes
   0 No
   - Not answered

b. During the past six months how many sessions have you had with a doctor, psychiatrist, or counselor for these problems (other than those when you were an inpatient in the hospital)?
   0 None, had treatment only as an inpatient
   1 Less than 4 sessions (only occasionally or for evaluation)
   2 4-12 sessions
   3 13 or more sessions
   - Not answered

c. Are you still receiving this help?
   1 Yes
   0 No
   - Not answered

d. Do you feel that you need treatment or counseling for personal or family problems or for nervous or emotional problems?
1 Yes
0 No
- Not answered

PSYCHOTROPIC DRUGS

(8) Have you taken any prescription medicine for your nerves in the past six months, like medicine to calm you down or to help depression?
1 Yes
0 No
- Not answered

[IF "NO" SKIP TO b.; IF "YES" ASK a. AND b.]

a. Are you still taking it?
1 Yes
0 No
- Not answered

b. Do you feel you need this kind of medicine?
1 Yes
0 No
- Not answered

PERSONAL CARE SERVICES

(9) In the past six months did someone have to help you with your personal care, for example helping you to bathe or dress, feeding you, or helping you with toilet care? [EXCLUDE PERSONAL CARE WHILE IN A HOSPITAL.]
1 Yes
0 No
- Not answered

[IF "NO" SKIP TO c.; IF "YES" ASK a., b., c, AND d.]

a. Who helped you in this way?

1 YES	0 NO	
		Unpaid family member
		Unpaid friend
		Someone hired to help you in this way or someone fi an agency

b. On the average, how much time per day has this person helped you to bathe, dress, eat, go to the toilet, etc.?
   1 Less than ½ hour per day
   2 ½ to 1½ hours per day
   3 More than 1½ hours per day
   - Not answered

c. Are you still being helped in this way?
   1 Yes
   0 No
   - Not answered

d. Do you feel you need help with bathing, dressing, eating, or going to the toilet, etc.?
   1 Yes
   0 No
   - Not answered

NURSING CARE

(10) During the past six months have you had any nursing care, in other words did a nurse or someone else give you treatments or medications prescribed by a doctor?
[EXCLUDE NURSING CARE WHILE IN THE HOSPITAL.]
   1 Yes
   0 No
   - Not answered

[IF "NO" SKIP TO e.; IF "YES" ASK a., b., c., d., AND e.]

a. Who helped you in this way?

1 YES	0 NO	
		Unpaid family member
		Unpaid friend
		Someone hired to help you in this way or someone from an agency

b. On the average, how many hours per day did you receive this help?
   0 Only occasionally, not every day
   1 Gave oral medicine only
   2 Less than ½ hour per day
   3 ½ to 1 hour per day
   4 More than 1 hour per day
   - Not answered

c. For how long did you have this help within the past six months?
1 Less than one month
2 1-3 months
3 More than 3 months
- Not answered

d. Are you still receiving nursing care?
1 Yes
0 No
- Not answered

e. Do you feel you need nursing care?
1 Yes
0 No
- Not answered

PHYSICAL THERAPY

(13) During the past six months have you received physical therapy?
1 Yes
0 No
- Not answered

[IF "NO" SKIP TO d.; IF "YES" ASK a., b., c., AND d.]

a. Who gave you physical therapy or helped you with it?

1 YES	0 NO	
		Unpaid family member
		Unpaid friend
		Someone hired to provide this or someone from an agency

b. On the average how many times a week did someone help you with your physical therapy activities?
1 Less than once a week
2 Once a week
3 2 or more times a week
- Not answered

c. Are you still receiving physical therapy?
1 Yes
0 No
- Not answered

d. Do you feel you need physical therapy?
1 Yes
0 No
- Not answered

CONTINUOUS SUPERVISION

(14) During the past six months was there any period when someone had to be with you all the time to look after you?

1 Yes
0 No
- Not answered

[IF "NO" SKIP TO c.; IF "YES" ASK a., b., AND c.]

a. Who looked after you?

1 YES	0 NO	
		Unpaid family member
		Unpaid friend
		Someone hired to help you in this way or someone from an agency

b. Do you still have to have someone with you all the time to look after you?

1 Yes
0 No
- Not answered

c.. Do you feel you need to have someone with you all the time to look after you?

1 . Yes
0 . No
-.. Not answered

CHECKING SERVICES

(15) [IF S IS STILL RECEIVING CONTINUOUS SUPERVISION ASK ONLY c.] [PERSONS WHO NEED CHECKING WHO ARE LIVING IN INSTITUTIONS OR WITH FAMILY MEMBERS MAY BE PRESUMED TO BE RECEIVING IT.]

During the past six months have you had someone regularly (at least five times a week) check on you by phone or in person to make sure you were alright?

1 . Yes
0 No
- Not answered

[IF "NO" SKIP TO c.; IF "YES" ASK a., b., AND c.]

a. Who checked on you?

1 YES	0 NO	
		Unpaid family member
		Unpaid friend
		Someone from an agency, a volunteer, or someone hired to help you

b. Is someone still checking on you at least five times a week?
1 Yes
0 No
- Not answered

c. Do you feel you need to have someone check on you regularly (at least five times a week) by phone or in person to make sure you are alright? [CIRCLE "NO", IF S FELT HE NEEDED CONTINUOUS SUPERVISION (14c.)]
1 Yes
0 No
- Not answered

RELOCATION AND PLACEMENT SERVICES

(16) In the past six months have you had any help in finding a new place to live, or in making arrangements to move in?
[THIS INCLUDES PLACEMENT IN INSTITUTIONS.]
1 Yes
0 No
- Not answered

[IF "NO" SKIP TO b.; IF "YES" ASK a., AND b.]

a. Who helped you with this?

1 YES	0 NO	
		Unpaid family member
		Unpaid friend
		Other, such as someone from an agency

b. Do you feel you need help in finding a (another) place to live?
1 Yes
0 No
- Not answered

HOMEMAKER-HOUSEHOLD SERVICES

(17) During the past six months did someone have to help you regularly with routine household chores such as cleaning, washing clothes, etc.? That is did your wife/husband or someone else have to do them because you were unable to?

1 Yes
0 No
- Not answered

[IF "NO" SKIP TO d.; IF "YES" ASK a., b., c., AND d.]

a. Who helped with household chores?

1 YES	0 NO	
		Unpaid family member
		Unpaid friend
		Other, such as paid helper or agency person

b. For about how many hours a week did you have to have help with household chores?

1 Less than 4 hours a week
2 4-8 hours a week (a half-day to a day)
3 9 or more hours a week (more than one day a week)
- Not answered

c. Are you still getting this kind of help?

1 Yes
0 No
- Not answered

d. Do you feel you need help with routine housework?

1 Yes
0 No
- Not answered

MEAL PREPARATION

(18) During the past six months did someone regularly have to prepare meals for you? That is did your wife/husband or someone else regularly cook because you were unable to, or did you have to go out for meals?

1 Yes
0 No
- Not answered

[IF "NO" SKIP TO c.; IF "YES" ASK a., b., AND c.]

a. Who prepared meals for you?

1 YES	0 NO	
		Unpaid family member
		Unpaid friend
		Other, such as a paid helper or agency person

b. Is someone still having to prepare meals for you?
1 Yes
0 No
- Not answered

c. Do you feel that you need to have someone regularly prepare meals for you because you can't do it yourself?
1 Yes
0 No
- Not answered

ADMINISTRATIVE, LEGAL AND PROTECTIVE SERVICES

(19) During the past six months has anyone helped you with any legal matters or with managing your personal business affairs or handling your money, for example paying your bills for you?
1 Yes
0 No
- Not answered

[IF "NO" SKIP TO c.; IF "YES" ASK a., b., AND c.]

a. Who helped you?

1 YES	0 NO	
		Family member
		Friend
		A lawyer, the Legal Aid Society, other agency personnel, or someone hired to help you

b. Are you still getting help with legal matters or with managing your personal business affairs?
1 Yes
0 No
- Not answered

c. Do you think you need help with these matters?
   1 Yes
   0 No
   - Not answered

SYSTEMATIC MULTIDIMENSIONAL EVALUATION

(20) In the past six months has anyone like a doctor or social worker thoroughly reviewed and evaluated your overall condition including your health, your mental health, and your social and financial situation?
   1 Yes
   0 No
   - Not answered

a. Do you think you need to have someone review and evaluate your overall condition in this way?
   1 Yes
   0 No
   - Not answered

COORDINATION, INFORMATION AND REFERRAL SERVICES

(24) During the past six months did someone see to it that you got the kinds of help you needed? In other words did someone give you information about the kind of help that is available or put you in touch with those who could help you?
   1 Yes
   0 No
   - Not answered

[IF "NO" SKIP TO c.; IF "YES" ASK a., b., AND c.]

a. Who was this person?

1 YES	0 NO	
		Family member
		Friend
		Someone from an agency

b. Is there still someone who sees to it that you get the kinds of help you need? In other words is there someone who gives you information about the kind of help that is available or puts you in touch with those who can help you?
   1 Yes
   0 No
   - Not answered

c. Do you feel you need to have someone organize or coordinate the kinds of help you need and make arrangements for you to get them?
   1 Yes
   0 No
   - Not answered

72. QUESTION 71 WAS ASKED OF:
   1 Subject
   2 Informant
   3 Both

CONCLUDING STATEMENT TO THE SUBJECT

[MAKE A BRIEF CONCLUDING STATEMENT TO THE SUBJECT INDICATING THE CONCLUSION OF THE INTERVIEW AND EXPRESSING YOUR APPRECIATION FOR HER/HIS COOPERATION.]

QUESTIONS TO BE ASKED OF AN INFORMANT
BASED ON HIS KNOWLEDGE OF THE SUBJECT

[IF THE SUBJECT IS UNRELIABLE THESE QUESTIONS MUST BE ASKED OF AN INFORMANT.]
[IF THE SUBJECT IS RELIABLE, THE QUESTIONS MUST BE ASKED IF AN INFORMANT IS AVAILABLE.]

SOCIAL RESOURCES

73. How well does ..... (Subject) get along with his/her family and friends--very well, fairly well, or poorly (has considerable trouble or conflict with them)?
    3 Very well
    2 Fairly well (has some conflict or trouble with them)
    1 Poorly (has considerable trouble or conflict with them)
    - Not answered

74. Is there someone who would help ..... (Subject) at all if he/she were sick or disabled, for example his/her husband or wife, a member of the family, or a friend?
    1 Yes
    0 No
    - Not answered

[IF "YES" ASK a. AND b.]

a. [CIRCLE THE MOST APPROPRIATE.]
   Is there someone outside of this place who would take care of him/her as long as needed, or only for a short time, or only someone who would help now and then (for example, taking him/her to the doctor, fixing lunch, etc.)?
   3 Someone who would take care of Subject indefinitely (as long as needed)
   2 Someone who would take care of Subject a short time (a few weeks to six months)
   1 Someone who would help him now and then (taking him to the doctor or fixing lunch, etc.)
   - Not answered

b. Who is this person?

   Name.....

   Relationship .....

   Code: Spouse = 1, Sibling = 2, Offspring = 3, Grandchild = 4, Other kin = 5, Friend = 6, Other = 7

ECONOMIC RESOURCES

75. In your opinion are ..... 's (Subject's) needs for the following basic necessities being well met, barely met, or are they not being met?

[CHECK THE APPROPRIATE BOX FOR EACH NEED.]

2 WELL MET	1 BARELY MET	0 NOT MET	
			Food
			Housing
			Clothing
			Medical care
			Small luxuries

MENTAL HEALTH

76. Does..... (Subject) show good, common sense in making judgments and decisions?
    1 Yes
    0 No
    - Not answered

77. Is..... (Subject) able to handle (cope with) major problems which occur in his/her life?
    1 Yes
    0 No
    - Not answered

78. Do you feel that..... (Subject) finds life exciting and enjoyable?
    1 Yes
    0 No
    - Not answered

79. How would you rate .....'s (Subject's) mental or emotional health or ability to think at the present time compared to the average person living independently--excellent, good, fair, or poor?
    3 Excellent
    2 Good
    1 Fair
    0 Poor
    - Not answered

80. Is .....(Subject's) mental or emotional health or ability to think--better, about the same, or worse than it was five years ago?
    2 Better
    1 About the same
    0 Worse
    - Not answered

PHYSICAL HEALTH

81. How would you rate ..... (Subject's) health at the present time--excellent, good, fair, or poor?
    3 Excellent
    2 Good
    1 Fair
    0 Poor
    - Not answered

82. How much do ..... (Subject's) health troubles stand in the way of his/her doing the things he/she wants to do--not at all, a little (some), or a great deal?
    2 Not at all
    1 A little (some)
    0 A great deal
    - Not answered

[THE REMAINING QUESTIONS ARE TO BE ANSWERED BY THE INTERVIEWER IMMEDIATELY AFTER LEAVING THE INTERVIEW SITE.]

83. Length of interview.....
    Minutes

84. Factual information obtained from:
    1 Subject
    2 Relative
    3 Other [SPECIFY.] .....

85. Factual questions (obtained from Subject and/or informant) are
    1 Completely reliable
    2 Reliable on most items
    3 Reliable on only a few items
    4 Completely unreliable

86. Subjective questions (those in boxes, obtained from Subject only) are:
    1 Completely reliable
    2 Reliable on most items
    3 Reliable on only a few items
    4 Completely unreliable
    5 Not obtained

[IF 5 ANSWER a.]

a. Why didn't the Subject answer the subjective question? [BE SPECIFIC.]

.....

.....

SOCIAL RESOURCES

87. Which of the following best describes the availability of help for the Subject if he/she were sick or disabled?

[CIRCLE THE MOST APPROPRIATE.]

3 At least one person could and would take care of the Subject indefinitely (as long as needed).
2 At least one person could and would take care of the Subject for a short time (a few weeks to 6 months).
1 Help would only be available now and then for such things as taking him/her to the doctor, fixing lunch, etc.
0 No help at all (except possible emergency help) would be available.

88. Which of the following best describes the Subject's social relationship?

[CIRCLE THE MOST APPROPRIATE.]

3 Very satisfactory, extensive
2 Fairly, satisfactory, adequate
1 Unsatisfactory, of poor quality, few

ECONOMIC RESOURCES

89. In your opinion which of the following best describes the Subject's income?
    1 Ample
    2 Satisfactory
    3 Somewhat inadequate
    4 Totally inadequate
    5 No income at all

90. In your opinion does the Subject have any financial reserves?
    1 Yes, has reserves
    0 No, has (little or) no reserves

91. In your opinion which of the following statements best describes the extent to which the Subject's needs are being met?
    1 Food, housing, clothing, and medical needs are met; Subject can afford small luxuries.
    2 Food, housing, clothing, and medical needs are met; Subject cannot afford small luxuries
    3 Either food, or housing, or clothing, or medical needs are unmet; Subject cannot afford small luxuries.
    4 Two or more basic needs (housing, food, clothing, medical care) are unmet; Subject cannot afford small luxuries.

MENTAL HEALTH

92. Is it your impression that the Subject shows good, common sense in making judgments and decisions?
    1 Yes
    0 No
    - Not answered

93. Is it your impression that the Subject is able to handle (cope with) major problems which occur in his/her life?
    1 Yes
    0 No
    - Not answered

94. Is it your impression that the Subject finds life exciting and enjoyable?
    1 Yes
    0 No
    - Not answered

95. During the interview did the Subject's behavior strike you as:

[CHECK "YES" OR "NO" FOR EACH OF THE FOLLOWING.]

1 YES	0 NO	
		Mentally alert and stimulating
		Pleasant and cooperative
		Depressed and/or tearful
		Withdrawn or lethargic
		Fearful, anxious, or extremely tense
		Full of unrealistic physical complaints
		Suspicious (more than reasonable)
		Bizarre or inappropriate in thought or action
		Excessively talkative or overly jovial, or elated

PHYSICAL HEALTH

96. Is the Subject either extremely overweight, or malnourished and emaciated?
    - 0 No
    - 1 Yes, extremely overweight
    - 2 Yes, malnourished or emaciated
    - - Not answered

SOCIAL RESOURCES RATING SCALE

97. [RATE THE CURRENT SOCIAL RESOURCES OF THE PERSON BEING EVALUATED ALONG THE SIX-POINT SCALE PRESENTED BELOW. CIRCLE THE *ONE* NUMBER WHICH BEST DESCRIBES THE PERSON'S PRESENT CIRCUMSTANCES. SOCIAL RESOURCES QUESTIONS ARE NUMBERS 6-14, 73, 74, 87, AND 88.]

1. *Excellent social resources.*
   Social relationships are very satisfying and extensive; at least one person would take care of him/her indefinitely.

2. *Good social resources.*
   Social relationships are fairly satisfying and adequate and at least one person would take care of him/her indefinitely.
   OR
   Social relationships are very satisfying and extensive; and only short term help is available.

3. *Mildly socially impaired.*
   Social relationships are unsatisfactory, of poor quality, few, but at least one person would take care of him/her indefinitely.
   OR
   Social relationships are fairly satisfactory, adequate; and only short term help is available.

4. *Moderately socially impaired.*
   Social relationships are unsatisfactory, of poor quality, few; and only short term care is available.
   OR
   Social relationships are unsatisfactory, of poor quality, few; and help would only be available now and then.

5. *Severely socially impaired.*
   Social relationships are unsatisfactory, of poor quality, few; and help would only be available now and then.
   OR
   Social relationships are at least satisfactory or adequate; but help is not even available now and then.

6. *Totally socially impaired.*
   Social relationships are unsatisfactory, of poor quality, few; and help is not even available now and then.

ECONOMIC RESOURCES RATING SCALE

98. [RATE THE CURRENT ECONOMIC RESOURCES OF THE PERSON BEING EVALUATED ALONG THE SIX-POINT SCALE PRESENTED BELOW. CIRCLE THE *ONE* NUMBER WHICH BEST DESCRIBES THE PERSON'S PRESENT CIRCUMSTANCES. ECONOMIC QUESTIONS ARE NUMBERS 15-30, 75, AND 89-91.]

1. *Economic resources are excellent.*
   Income is ample; Subject has reserves

2. *Economic resources are satisfactory.*
   Income is ample; Subject has no reserves
   or
   Income is adequate; Subject has reserves.

3. *Economic resources are mildly impaired.*
   Income is adequate; Subject has no reserves
   or
   Income is somewhat inadequate, Subject has reserves.

4. *Economic resources are moderately impaired.*
   Income is somewhat inadequate; Subject has no reserves.

5. *Economic resources are severely impaired.*
   Income is totally inadequate; Subject may or may not have reserves.

6. *Economic resources are completely impaired.*
   Subject is destitute, completely without income or reserves.

[INCOME IS CONSIDERED TO BE ADEQUATE IF ALL THE SUBJECT'S NEEDS ARE BEING MET.]

MENTAL HEALTH RATING SCALE

99. [RATE THE CURRENT MENTAL FUNCTIONING OF THE PERSON BEING EVALUATED ALONG THE SIX-POINT SCALE PRESENTED BELOW. CIRCLE THE *ONE* NUMBER WHICH BEST DESCRIBES THE PERSON'S PRESENT FUNCTIONING. MENTAL HEALTH QUESTIONS ARE THE PRELIMINARY QUESTIONNAIRE, AND NUMBERS 31-36, 76-80, AND 92-95.]

1. *Outstanding mental health.*
   Intellectually alert and clearly enjoying life.
   Manages routine and major problems in his/her life with ease and is free from any psychiatric symptoms.

2. *Good mental health.*
   Handles both routine and major problems in his/her life satisfactorily and is intellectually intact and free of psychiatric symptoms.

3. *Mildly mentally impaired.*
   Has mild psychiatric symptoms and/or mild intellectual impairment. Continues to handle routine, though not major, problems in his/her life satisfactorily.

4. *Moderately mentally impaired.*
   Has definite psychiatric symptoms, and/or moderate intellectual impairment. Able to make routine, common-sense decisions, but unable to handle major problems in his/her life.

5. *Severely mentally impaired.*
   Has severe psychiatric symptoms and/or severe intellectual impairment, which interfere with routine judgments and decision making in every day life.

6. *Completely mentally impaired.*
   Grossly psychotic or completely impaired intellectually. Requires either intermittent or constant supervision because of clearly abnormal or potentially harmful behavior.

PHYSICAL HEALTH RATING SCALE

100. [RATE THE CURRENT PHYSICAL FUNCTIONING OF THE PERSON BEING EVALUATED ALONG THE SIX-POINT SCALE PRESENTED BELOW. CIRCLE THE *ONE* NUMBER WHICH BEST DESCRIBES THE PERSON'S PRESENT FUNCTIONING. PHYSICAL HEALTH QUESTIONS ARE NUMBERS 37-55, 81, 82, AND 96.]

1. *In excellent physical health*.
   Engages in vigorous physical activity, either regularly or at least from time to time.

2. *In good physical health*.
   No significant illnesses or disabilities. Only routine medical care such as annual check ups required.

3. *Mildly physically impaired*.
   Has only minor illnesses and/or disabilities which might benefit from medical treatment or corrective measures.

4. *Moderately physically impaired*.
   Has one or more diseases or disabilities which are either painful or which require substantial medical treatment.

5. *Severely physically impaired*.
   Has one or more illnesses or disabilities which are either severely painful or life threatening, or which require extensive medical treatment.

6. *Totally physically impaired*.
   Confined to bed and requiring full time medical assistance or nursing care to maintain vital bodily functions.

PERFORMANCE RATING SCALE FOR ACTIVITIES OF DAILY LIVING

101. [RATE THE CURRENT MENTAL FUNCTIONING OF THE PERSON BEING EVALUATED ON THE SIX-POINT SCALE PRESENTED BELOW. CIRCLE THE *ONE* NUMBER WHICH BEST DESCRIBES THE PERSON'S PRESENT PERFORMANCE. ACTIVITIES OF DAILY LIVING QUESTIONS ARE NUMBERS 56-69.]

1. *Excellent ADL capacity*.
   Can perform all of the Activities of Daily Living without assistance and with ease.

2. *Good ADL capacity*.
   Can perform all of the Activities of Daily Living without assistance.

3. *Mildly impaired ADL capacity*.
   Can perform all but one to three of the Activities of Daily Living. Some help is required with one to three, but not necessarily every day. Can get through any single day without help. Is able to prepare his/her own meals.

4. *Moderately impaired ADL capacity*.
   Regularly requires assistance with at least four Activities of Daily Living but is able to get through any single day without help. Or regularly requires help with meal preparation.

5. *Severely impaired ADL capacity*.
   Needs help each day but not necessarily throughout the day or night with many of the Activities of Daily Living.

6. *Completely impaired ADL capacity*.
   Needs help throughout the day and/or night to carry out the Activities of Daily Living.

.....

Summary of Ratings

_____ Social Resources .....

_____ Economic Resources _____ .....

_____ Mental Health _____ _____

_____ Physical Health _____ _____

_____ Activities of Daily Living _____ _____

Cumulative Impairment Score .....
(Sum of the five ratings)

PATIENT GENERATED INDEX

The Patient Generated Index is a self-administered quality of life scale. The questionnaire quantifies the effect of a medical condition on the patients' quality of life in such a way that has meaning and relevance in the context of their daily lives.

Abbreviated Name: PGI
Author(s): Danny Ruta & Andrew Garratt
Purpose: To measure individualised quality of life
Population: Adult
Age Range : 16 to 85 years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-/ Interviewer-administered
Time required:	1-2 minutes
Response Options:	Likert scale from 0 to 100 in multiples of 10
Scoring:	Global score
Score Direction:	Higher scores show better QoL
Weighting:	Yes: the patient rates how he/she is affected in each of 5 selected activities and then allocate a total of 60 point to ponderate the different activities so as to represents the relative importance of potential improvements in that area.

Number of Items: 15
Original Language: English

Contact for information and permission to use:

Dr Danny Ruta
Senior Lecturer in Epidemiology and Public Health
School of Population and Health Sciences
University of Newcastle
William Leech Building
The Medical School
Framlington Place
Newcastle upon Tyne NE2 4HH
Phone: +44 (0)191 222 8897
Mobile: +44 (0)796 991 7016
Email: danny.ruta@ncl.ac.uk

Andrew Garratt
Unit of Health-Care Epidemiology,
Institute of Health Sciences
University of Oxford,
Old Road,
Oxford, OX3 7LF, UK.
Phone: 01865 227157
Fax: 01865 226993
Email: andrew.garratt@uhce.ox.ac.uk

Dimensions covered by the questionnaire :

No dimensions: the patient is asked to give the five most important areas or activities of life that are affected by its condition

Key References:

1. Ruta DA, Garratt AM et al. A new approach to the measurement of quality of life. The Patient Generated Index. Medical Care 1994;32(11):1109-1126

Quality of life has been defined as "the extent to which our hopes and ambitions are matched by experience." To improve a patient's quality of life through medical care would be to "narrow the gap between a patient's hopes and expectations and what actually happens." Using the above definition as a conceptual basis, we produced a self-administered, Patient-Generated Index (PGI) of quality of life. The PGI was completed by 359 patients presenting with low back pain. The validity of the measure was assessed by correlating patients' PGI scores with a well-validated health profile, the Short-Form 36-item Health Survey (SF-36), and with their scores on a clinical back pain questionnaire. Stepwise multiple regression was then used to model the relationship between the PGI score and the SF-36. Patients' PGI scores showed a high correlation with SF-36 scales measuring pain, social functioning, and role limitations attributable to physical problems, and with the clinical questionnaire. Together with whether a person was retired or not, these health variables were able to explain 25% of the variance in PGI scores. Patient generated index scores were significantly lower in patients referred to hospital compared with those managed solely in general practice and tended to reflect the general practitioner's assessment of symptom severity. We conclude that it is possible to construct a questionnaire that quantifies the effect of a medical condition on patients' quality of life in a way that has meaning and relevance in the context of their daily lives. The PGI has considerable potential for routine use in a wide range of clinical conditions for which the measurement of outcome has hitherto proved very difficult.

Some thoughts on the use of the Patient Generated Index (PGI) of Quality of Life in clinical trials to evaluate the Thermablate EAS

Dr Danny Ruta, Senior Lecturer in Epidemiology and Public Health, University of Newcastle, UK

Why measure 'Individual' QoL and why use the PGI?

If the major goal of treatment with the Thermablate EAS is to improve the quality of life for women with excessive menstrual bleeding, then the endpoints currently used in clinical trials may fall short as measures of outcome. For example objectively measured blood loss has been shown to correlate poorly with a woman's subjective assessment of her blood loss, and with her subjective well-being. Both generic and menorrhagia-specific patient assessed outcome measures acknowledge the multidimensional nature of health and the need to reflect the patient's perspective. Our study found a high level of agreement between generic health status, as measured by the SF-36, and clinical disease severity, as measured by our patient completed menorrhagia questionnaire. However, the choice of dimensions (e.g. physical function in the SF-36) and items (e.g. problems with soiling/staining of outerclothes in the menorrhagia questionnaire), and the values attached to them are imposed on the patient regardless of their relevance to that particular individual. This has led some to conclude that the majority of outcome measures used in clinical trials, even patient reported measures, 'fail to address the diversity of priorities and concerns of respondents and the varying weights and values which they attach to their concerns'.

The Patient Generated Index (PGI) of QoL was designed to overcome this fundamental limitation of conventional outcome measures. The PGI is a doctor or nurse administered (initially, and thereafter self-administered) questionnaire taking 5 -10 minutes to complete. However it is patient generated because it asks patients to select those aspects of their life that they consider of prime importance, and which are most affected by their condition. It then asks them to rate how far they are from their ideal in each chosen area. Finally it asks them to weight the relative importance of the different areas for their overall QoL. It generates a QoL index between 0% and 100%.

Evidence for the validity of the PGI in patients with menorrhagia

The original version of the PGI was successfully administered to 200 patients who presented in general practice with menorrhagia between March and June 1991. The menorrhagia questionnaire and the SF-36 were also completed by patients at the same time. 61 patients completed all three measures at one year follow-up.

At baseline, patients' quality of life scores as measured by the PGI were moderately correlated (0.23 – 0.29, $p<1\%$) with scores for pain, general health, energy/fatigue, mental health, role limitations due to physical problems, and social functioning. Quality of life also showed a moderate correlation (0.25, $p<1\%$) with clinical severity as measured by the menorrhagia questionnaire. 15% of the variation in PGI quality of life scores could be explained by social function, pain, and a woman's age (older women reporting higher perceived QoL).

The responsiveness of the three outcome measures was assessed by comparing baseline and one year assessments for 61 patients. Quality of life as measured by the PGI showed a highly statistically

significant mean improvement of 8% ($p<1\%$). The PGI was found to be far more responsive than all eight dimensions of the SF-36. The PGI was found to be only slightly less responsive to clinical change over time than the menorrhagia questionnaire.

Which patient reported outcome measures should be used to evaluate the Thermablate EAS in a clinical trial?

There is a good case to be made for including the SF-36 (or the SF-12), the menorrhagia questionnaire, and the PGI in any future trials of Thermablate EAS treatment for menorrhagia, for the following reasons:

- The SF-36 (and SF-12) is widely used in clinical research. It is therefore perceived as a credible outcome measure by many physicians and the wealth of normative and other published data facilitates a clinical interpretation of any score differences observed in a trial. As a generic health status profile measure it permits an assessment of the impact of Thermablate EAS treatment on specific dimensions of general health;

- The menorrhagia questionnaire is based on the type of questions asked by physicians when taking a gynaecological history and has been rigorously validated. It therefore provides far more clinically meaningful information on the impact of Thermablate EAS treatment on the severity of specific symptoms and signs of menorrhagia. It is also very responsive to clinical change over the time periods of interest to clinicians;

- The PGI focuses on those aspects of patients' lives that they consider of greatest importance and relevance to their overall quality of life, and which are specifically affected by their excessive menstrual loss. It has been rigorously validated in this patient group. It therefore provides a far more meaningful assessment of the impact of Thermablate EAS treatment from the patient's perspective. It is also more responsive to clinically important change over time.

Together these three instruments provide a complete assessment of the effectiveness of Thermablate EAS treatment in a clinical trial context.

Modifying the PGI to improve its validity, reliability, and responsiveness in a trial of Thermablate EAS

The original PGI has undergone significant development in order to improve its psychometric properties, increase its health-related focus in a trial context, and yet still confer distinct advantages as an individualised QoL measure relevant to patients. Key differences from the original are:

- The first stage now focuses entirely on those areas of life affected by the patients health;

- The second stage has a simplified 7-point scale with anchor statements;

- The third stage has a simplified method of spending points and revised wording designed to reduce ambiguity in the weighting of life areas.

Ricardo Romero at MDMI has adapted this latest version for use in clinical trials of Thermablate EAS treatment where a pre-treatment assessment, and 1, 3, 6 and 12 month follow-up assessments are required. The pre-treatment assessment asks the patient to think about their QoL over the previous 3 months. This time period will ensure that any impact of excessive menstrual blood loss on QoL from at least two

menstruations is captured by the tool. The one month post-treatment assessment will obviously ask about the last four weeks. 3, 6, and 12 month assessments would ask about the last 3 months again.

It is recommended that the following steps are undertaken in the final development and subsequent administration of the PGI in a Thermablate EAS trial

1. The MDMI-modified version should be piloted with 2-5 patients in order to refine the trigger list of commonly mentioned areas included in the first stage. Trigger areas should be selected for the final tool so that examples of different types of area are provided (e.g. broad areas such as 'family life', symptoms, disabilities, handicaps, and personal or idiosyncratic areas such as 'wearing my party dress'). This will give patients an indication that they can think as widely or narrowly as they wish, and that there is no such thing as a 'silly' or 'wrong' answer.

2. In order to maximise the reliability and responsiveness of the tool, the areas which were nominated by a patient at their pre-treatment assessment should be included in the follow-up questionnaire (i.e. part 1 is pre-completed for the patient prior to administration). The trial researchers can then elect to administer the follow-up questionnaire in one of three ways: 1) the patient is asked only to rate the life areas nominated at baseline; 2) the patient is shown the original areas and given the opportunity to remove or add areas before proceeding to the next stage; and 3) the patient is first asked only to rate the areas of life nominated at baseline, and then offered the opportunity to complete a fresh PGI questionnaire. The first method is likely to increase the responsiveness of the PGI to the effects of treatment. The second method may result in reduced sensitivity to change but may provide a more meaningful assessment in the context of the patient's present life circumstances (e.g. the patient may have nominated 'my job' at pre-treatment assessment but may now have re-prioritised her life such that her job is no longer an important life area). The third method permits the calculation of 2 separate QoL index scores.

3. If there is evidence to suggest that Thermablate EAS treatment may cause side effects in some patients, trial researchers may wish to consider modifying the PGI to take capture the impact of such side effects on QoL. For example the PGI could be re-worded to ask:

   '*Now please complete the questionnaire to tell us how your life is currently affected by your* ***menstrual blood loss and its treatment'***

Calculating the PGI QoL Index Score

The example below illustrates how the PGI Index score is generated

Example: 42 yr old lady presenting with excessive menstrual bleeding

Part 1 List Areas	Part 2 Score Areas	Part 3 Spend Points
1. Interferes with my job	3 out of 6	4
2. Get really tired	2 out of 6	2
3. Embarrassment	4 out of 6	3
4. Can't wear what I'd like	2 out of 6	1
5. ----------		
6. All other areas of your life affected by your menstrual blood loss	5 out of 6	0

PGI Index Score as a % = [sum of (area score x points spent/10)] / 6 x 100

In this example:

= [3 x 0.4 + 2 x 0.2 + 4 x 0.3 + 2 x 0.1 + 5 x 0] / 6 x 100

= [1.2 + 0.4 + 1.2 + 0.2 + 0] / 6 x 100

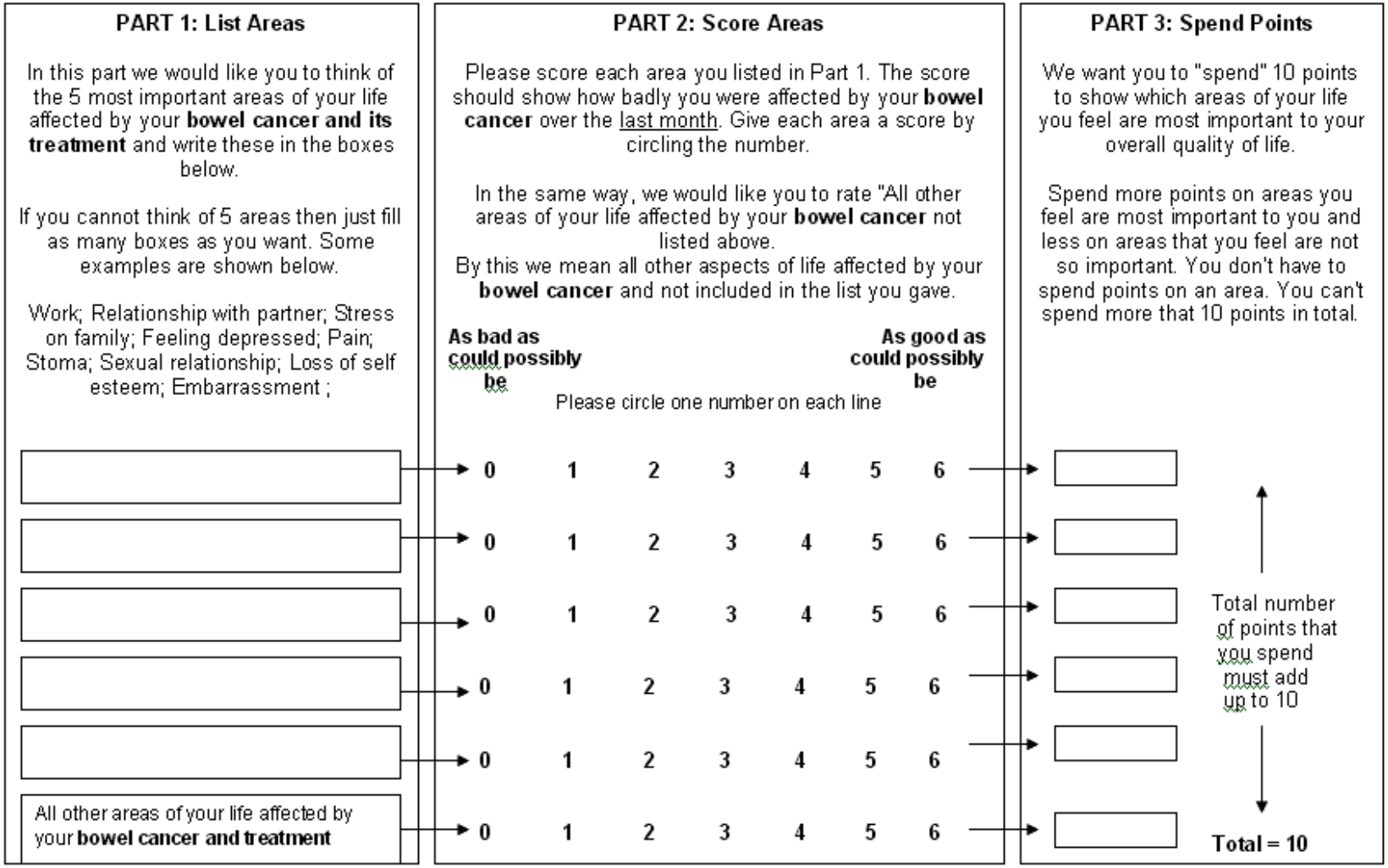
= 3/6 x 100 = 50% (where 100% is as good as could possibly be)

Note that this lady only nominated 4 specific life areas. Patients can nominate between one and five areas. If a patient cannot nominate any areas at all at baseline, the implication is that her life is not affected by her menorrhagia.

Note also that a simple average of the score areas (i.e. excluding the weighting exercise in part 3) for the five life areas scored by this lady would give have given her a QoL score of = 53%. The PGI score is lower because the Index gives greater weight to those life areas that the patient considers to be more important (i.e. in this lady's case interference with her job, and embarrassment). 'All other areas of life affected by menstrual blood loss' does not contribute to this lady's PGI Index Score even though this area of her life was scored highly. This is because she allocated no points to this area in part 3.

It is possible for a patient to spend all her points on one area. If this lady had chosen to spend 10 points on area 2 (getting really tired), her PGI QoL Index score would have been 2/6 x 100 = 33%. If on the other hand she had spent all her points on area 3 (embarrassment) her PGI QoL Index score would have been 4/6 x 100 = 67%.

Please complete the questionnaire to tell us how your life is currently affected by your **bowel cancer and its treatment** and how you would like to see it improve.



PERCEIVED QUALITY OF LIFE SCALE

The Perceived Quality of Life Scale (PQoL) is a measure based on a model defining quality of life as on evaluation of major categories of fundamental life needs. Scale items were developed using human needs theory (Maslow, 1943; Doyal and Gough, 1991) and interviews with different populations of older adults, well persons, and persons with disabilities to establish the content of the instrument. The measure is consistent with the needs based theory of quality of life (Hunt and McKenna, 1992) and the World Health Organization Definition of quality or life as people's "perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns"

Abbreviated Name: PQoL
Author(s): Donald L. Patrick, Marion Danis.
Purpose: To assess quality of life of patients with chronic diseases with various levels of wellness and disability.
Population: Adult
Age Range : 18 to 75 years.
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-/ Interviewer-administered
Time required:	5-10 minutes
Response Options:	11-point Likert scale
Scoring:	Global score: Minimum score: 0 / Maximum score: 10 Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 20
Original Language: English
Existing Translations : Norwegian, Spanish

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Contact for information and permission to use:

Donald L. Patrick, PhD, MSPH
Box 357660 H 689
University of Washington
1934 NE Pacific
Seattle WA 98195-7660 USA
Phone: 206 616 2981
Fax: 206 543 3964

Tu. Thur Canal St Research Office
146 N Canal Suite 310 Seattle 98103
Phone: 206 685 7252
Fax: 206 616 3135
E-Mail: donald@u.washington.edu

Dimensions covered by the questionnaire :

- Physical health
- Social health
- Cognitive health

Key References:

1. Patrick DL, Kinne S, Engelberg RA et al. Functional status and perceived quality of life in adults with and without chronic conditions. J Clin Epidemiol 2000;53(8):779-85

The objective of this study was to evaluate the association between self-reported functional status and quality of life in adults with and without chronic conditions. Data were obtained on functional status (Sickness Impact Profile, SIP), and perceived quality of life (Perceived Quality of Life Scale, PQoL) from 454 persons in nine groups with widely varying levels of functional status and disability. Multiple regression was used to analyze the association controlling for demographic characteristics (age, gender, educational level, income, marital status), self-rated health status, and depressive symptoms. PQoL was lowest for persons using wheelchairs and highest for older well adults. Scores decreased as SIP scores increased. Overall, being older, reporting better functional status, and having fewer depressive symptoms were significantly associated with higher quality of life (adjusted R(2) = 0.60). This pattern held for most subgroups, although the association was much lower for adults with AIDS and younger well adults where ceiling effects were observed in functional status. Functional status and perceived quality of life are highly associated but are distinct in many populations. Depressive symptoms and self-rated health are important mediators of the relationship to include in future studies. Amelioration of depressive symptoms through environmental modification and individual treatment are potential strategies for improving on this association in adults with chronic conditions.

2. Patrick DL, Danis M, Southerland LI, Hong G. Quality of life following intensive care. J Gen Intern Med 1988; 3:218-23.

Evaluations of intensive care have largely focused on survival, cost, or functional status; however, these may not be the only outcomes of interest to patients, families, and health care providers. Quality of life is an important consideration in evaluating intensive care because it influences decisions about the use of life-sustaining treatment. A study was conducted to assess the quality of life of survivors of intensive care to determine the relationship of perceived quality of life to other outcomes of intensive care. Patients at least 55 years old who received medical intensive care during 1983 (n = 69) were interviewed to determine social characteristics, functional status, psychological well-being, and their perceived quality of life using a new 11-item Perceived Quality of Life scale. Functional status correlated only moderately with perceived quality of life (r = 0.49, p = 0.0001). Objective measures of patients' material and social resources did not predict satisfaction. To evaluate outcome adequately, it is necessary to assess perceptions of life quality from patients who have received life-sustaining treatment.

Information Sheet on the Perceived Quality of Life Scale (PQoL)

Commonly Asked Questions

What is the PQoL?

The Perceived Quality of Life Scale (PQoL) is a measure based on a model defining quality of life as evaluation of major categories of fundamental life needs. Scale items were developed using human needs theory (Maslow, 1943; Doyal and Gough, 1991) and interviews with different populations of older adults, well persons, and persons with disabilities to establish the content of the instrument. The measure is consistent with the needs based theory of quality of life (Hunt and McKenna, 1992) and the World Health Organization Definition of quality or life as people's "*perceptions of their position* in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns" [italics added] (Bonomi et al., 2000; WHOQoL Group, 1994).

Originally the PQoL was used in a briefer 12-item version for assessing the quality of life of persons following intensive care (Patrick et al., 1988). It was later expanded to 19 items plus a single global item to include evaluation of satisfaction with areas of functional status considered important to persons with varying levels of wellness and disability. Since its original use, it has been more widely applied to a number of different patient and general population groups. (See application references at end of this document).

This measure also incorporates the areas of dysfunction included in the Sickness Impact Profile (SIP) developed in the United States (Bergner et al, 1981) and the Functional Limitations Profile (FLP), a culturally-adapted and UK weighted version of the SIP developed in the United Kingdom (Patrick and Peach, 1989). The PQoL can be correlated with SIP or FLP Category Scores to investigate the relationship between functional status and satisfaction with functioning (see Patrick et al, 2000 on development of the PqoL).

The PQoL is also part of a generic health and quality of life outcomes package being developed at the University of Washington that includes the assessment of functional status using the Short Profile of Illness Impact developed from the SIP, the PQoL, and a current health state desirability or preference measure. For more information on this package and its development, contact Donald Patrick

Who developed the PQoL?

The PQoL was originally developed at the University of North Carolina, Chapel Hill by a team of researchers including Dr. Donald Patrick and Dr. Marion Danis. Later it was expanded and further developed by a team of researchers from the University of Washington, Seattle under the direction of Dr. Donald Patrick. Extensive testing of the PQoL has been conducted in cooperation with Group Health Cooperative of Puget Sound.

What are the PQoL Items?

The PQoL consists of the following 19 items, each with an 11-point response scale, in addition to a global item on happiness used for comparison purposes:

0 - Extremely dissatisfied/unhappy

1 or 2 - Somewhat dissatisfied/unhappy

3 or 4 - A little dissatisfied/unhappy

5 - Neither satisfied/happy or dissatisfied/unhappy

6 or 7 - A little satisfied/happy

8 or 9 - Somewhat satisfied/happy

10 - Extremely satisfied/happy

The 19 items measure the level of satisfaction; an additional item addressing happiness is used to examine convergent validity within the instrument. The additional item also uses a 0 – 10 scale to rate his/her happiness.

P 1 How ***dissatisfied*** or ***satisfied*** are you with your physical health (the health of your body)?

P 2 How ***dissatisfied*** or ***satisfied*** are you with how well you care for yourself, for example, preparing meals, bathing, or shopping?

C 3 How ***dissatisfied*** or ***satisfied*** are you with how well you think and remember?

P 4 How ***dissatisfied*** or ***satisfied*** are you with the amount of walking you do?

P 5 How ***dissatisfied*** or ***satisfied*** are you with how often you get outside the house, for example, going into town, using public transportation, or driving?

C 6 How ***dissatisfied*** or ***satisfied*** are you with how well you carry on a conversation, for example, speaking clearly, hearing others, or being understood

7 How ***dissatisfied*** or ***satisfied*** are you with the kind and amount of food you eat?

S 8 How ***dissatisfied*** or ***satisfied*** are you with how often you see or talk to your family and Friends?

S 9 How ***dissatisfied*** or ***satisfied*** are you with the help you get from your family and friends, for example, helping in an emergency, fixing your house, or doing errands?

S 10 How ***dissatisfied*** or ***satisfied*** are you with the help you give to your family and friends?

S 11 How ***dissatisfied*** or ***satisfied*** are you with your contribution to your community, for example, a neighborhood, religious, political or other group?

S 12 How ***dissatisfied*** or ***satisfied*** are you with your work situation, for example, your current job, retirement for any reason, or never having worked?

S 13 How ***dissatisfied*** or ***satisfied*** are you with the kind and amount of recreation or leisure you have?

S 14 How ***dissatisfied*** or ***satisfied*** are you with your level of sexual activity or lack of sexual activity?
S 15 How ***dissatisfied*** or ***satisfied*** are you with the way your income meets your needs?
S 16 How ***dissatisfied*** or ***satisfied*** are you with how respected you are by others?
S 17 How ***dissatisfied*** or ***satisfied*** are you with the meaning and purpose of your life?
S 18 How ***dissatisfied*** or ***satisfied*** are you with the amount of variety in your life?
P 19 How ***dissatisfied*** or ***satisfied*** are you with the amount and kind of sleep you get?

The single overall item uses a n 11-point response scale from extremely unhappy to very happy

S 20 How happy are you?

How is the PQoL scored?

Nineteen item scores and an overall score based on the mean or median of the 19 item scores are constructed. A population mean/median of 7.5 has been observed (N=3359). Interpretation of the measure in cross-sectional use is [< 7.5 score is Dissatisfied] and [> 7.5 score is Satisfied].

Subscale scores of physical, social, and cognitive health satisfaction (denoted by P, S, and C accordingly) can be used in further analysis as well as the overall score. Item 7 did not appear to fall into any factor and is best to use on its own.

For convergent validity, the overall PQoL score can be correlated with Item 20, the happiness rating. The Pearson's or ICC correlation coefficient should exceed 0.70.

How is the PQoL administered?

The PQoL can be either administered by an interviewer or self-administered in approximately 5 minutes.

PERCEIVED QUALITY OF LIFE SCALE© INFORMATION FOR USERS

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This document describes the development, scoring, and potential uses of the Perceived Quality of Life Scale (PQoL), a measure based on a model defining quality of life as evaluation of major categories of fundamental life needs. Scale items were developed using human needs theory (Maslow, 1943; Doyal and Gough, 1991) and interviews with different populations of older adults, well persons, and persons with disabilities to establish the content of the instrument. The measure is consistent with the needs based theory of quality of life (Hunt and McKenna, 1992) and the World Health Organization Definition of quality or life as people's "*perceptions of their position* in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns" [italics added] (Bonomi et al., 2000; WHOQoL Group, 1994).

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This measure also incorporates the areas of dysfunction included in the Sickness Impact Profile (SIP) developed in the United States (Bergner et al, 1981) and the Functional Limitations Profile (FLP), a culturally-adapted and UK weighted version of the SIP developed in the United Kingdom (Patrick and Peach, 1989). The PQoL can be correlated with SIP or FLP Category Scores to investigate the relationship between functional status and satisfaction with functioning (see Patrick et al, 2000 on development of the PQoL).

The PQoL is also part of a generic health and quality of life outcomes package being developed at the University of Washington that includes the assessment of functional status using the Short Profile of Illness Impact developed from the SIP, the PQoL, and a current health state desirability or preference measure. For more information on this package and its development, contact Donald Patrick

For additional information: Dr. Donald L. Patrick
Department of Health Services Box 357660
School of Public Health and Community Medicine
University of Washington
Seattle, WA 98195-7660

PHONE: (206) 616-2981
FAX: (206) 543-3964
E-MAIL: donald@u.washington.edu

Instructions for Interview Version

Instructions for Interviewers:

This questionnaire asks about satisfaction with health and life in general. For each item, the respondent is to rate their level of satisfaction on a scale from 0 to 10 where 0 is ***extremely dissatisfied*** and 10 is ***extremely satisfied***. Have the respondent look at the scale on a card (See CARD I below) and give you a number between 0 and 10. Record that number on the scale sheet. NOTE: The exception is item 20 that addresses happiness and is included for examination of convergent validity within the instrument. Here the respondent is to rate his/her happiness on a scale from 0 to 10 where 0 is ***extremely unhappy*** and 10 is ***extremely happy*** (See CARD 2 below). Total PQoL score should correlate highly with this single item.

Say to the Respondent:

I want to talk to you now about your satisfaction with your health and other fundamental aspects of your life. Some people are more or less satisfied or dissatisfied with the different aspects of their lives. We want you to think about your own life situation and tell us just how satisfied or dissatisfied you are. I want you to give us a number on a scale of 0 to 10 where 0 is extremely dissatisfied and 10 is extremely satisfied. I want you to look at the scale and give me a number between 0 and 10 which best represents how satisfied or dissatisfied you fell. SHOW RESPONDENT CARD 1 FOR ITEMS 1- 19 AND CARD 2 FOR ITEM 20).

If the Respondent has Difficulty with Direct Assignment of Number from 0-10

Some respondents unfamiliar with rating scales or with questionnaires in general may have difficulty in directly assigning a number from 0 to 10 to indicate their level of satisfaction/ dissatisfaction. For these respondents, a two or three step procedure can be followed. Verbal anchors on a card (satisfaction/dissatisfaction for items 1-19 and happy/unhappy for item 20) can be shown to these respondents as follows:

Extremely dissatisfied/unhappy	=	0
Somewhat dissatisfied/unhappy	=	1 or 2
A little dissatisfied/unhappy	=	3 0r 4
Neither satisfied/happy or dissatisfied/unhappy	=	5
A little satisfied/happy	=	6 or 7
Somewhat satisfied/happy	=	8 or 9
Extremely satisfied/happy	=	10

Ask the respondent to give you the word that best indicates his or her level of satisfaction/ happiness. For verbal categories that have two numerical scores, then ask the respondent to choose the lower number or higher number that indicates their perceived level of satisfaction/ happiness. Most respondents are able to choose between the two numbers. In cases where respondents cannot or refuse to choose one of the two numbers, then toss a coin to decide (heads=lower number, tails=higher number).

CARD 1

	0	1	2	3	4	5	6	7	8	9	10	
EXTREMELY DISSATISFIED												EXTREMELY SATISFIED

CARD 2

	0	1	2	3	4	5	6	7	8	9	10	
EXTREMELY UNHAPPY												EXTREMELY HAPPY

Recall Period:

In general, no recall period has been used with the PQoL as satisfaction "at the moment of instrument administration" is what is being requested. If all other instruments in the questionnaire have specific recall periods, it is wise to give a recall period to the PQoL as well. A recall period of "in the last week" or "in the last month" can be used. The PQoL, in usage with the Sickness Impact Profile, should contain "think of yourself today" which was the original intent of the SIP.

INSTRUCTIONS FOR PREPARING SELF-ADMINISTERED VERSION

In preparing your questionnaire for self-administration, please **NOTE** that the anchors of ***Extremely dissatisfied*** and ***Extremely satisfied*** should be **COMPLETELY OUTSIDE** the numbers **0** and **10** to indicate they are cognitive anchors outside the numbers. If they are put below the numbers, there may be a tendency of respondents to avoid using the extreme numbers.

For each question, please circle the number that indicates how dissatisfied or satisfied you are with that aspect of your life. A response of 5 means that you are neither dissatisfied nor satisfied.

P *1 How ***dissatisfied*** or ***satisfied*** are you with your physical health (the health of your body)? (*Please circle the number)*

0 1 2 3 4 5 6 7 8 9 10

EXTREMELY DISSATISFIED **EXTREMELY SATISFIED**

P 2 How ***dissatisfied*** or ***satisfied*** are you with how well you care for yourself, for example, preparing meals, bathing, or shopping? (*Please circle the number)*

0 1 2 3 4 5 6 7 8 9 10

EXTREMELY DISSATISFIED **EXTREMELY SATISFIED**

C *3 How ***dissatisfied*** or ***satisfied*** are you with how well you think and remember? (*Please circle the number)*

0 1 2 3 4 5 6 7 8 9 10

EXTREMELY DISSATISFIED **EXTREMELY SATISFIED**

P 4 How ***dissatisfied*** or ***satisfied*** are you with the amount of walking you do? (*Please circle the number)*

0 1 2 3 4 5 6 7 8 9 10

EXTREMELY DISSATISFIED **EXTREMELY SATISFIED**

P 5 How ***dissatisfied*** or ***satisfied*** are you with how often you get outside the house, for example, going into town, using public transportation, or driving? (*Please circle the number)*

0	1	2	3	4	5	6	7	8	9	10
EXTREMELY DISSATISFIED										**EXTREMELY SATISFIED**

C 6 How ***dissatisfied*** or ***satisfied*** are you with how well you carry on a conversation, for example, speaking clearly, hearing others, or being understood? (*Please circle the number)*

0	1	2	3	4	5	6	7	8	9	10
EXTREMELY DISSATISFIED										**EXTREMELY SATISFIED**

7 How ***dissatisfied*** or ***satisfied*** are you with the kind and amount of food you eat? (*Please circle the number)*

0	1	2	3	4	5	6	7	8	9	10
EXTREMELY DISSATISFIED										**EXTREMELY SATISFIED**

S *8 How ***dissatisfied*** or ***satisfied*** are you with how often you see or talk to your family and Friends? (*Please circle the number)*

0	1	2	3	4	5	6	7	8	9	10
EXTREMELY DISSATISFIED										**EXTREMELY SATISFIED**

S *9 How ***dissatisfied*** or ***satisfied*** are you with the help you get from your family and friends, for example, helping in an emergency, fixing your house, or doing errands? (*Please circle the number)*

0	1	2	3	4	5	6	7	8	9	10
EXTREMELY DISSATISFIED										**EXTREMELY SATISFIED**

S *10 How ***dissatisfied*** or ***satisfied*** are you with the help you give to your family and friends? (*Please circle the number)*

0	1	2	3	4	5	6	7	8	9	10
EXTREMELY DISSATISFIED										**EXTREMELY SATISFIED**

S *11 How ***dissatisfied*** or ***satisfied*** are you with your contribution to your community, for example, a neighborhood, religious, political or other group? (*Please circle the number*)

0	1	2	3	4	5	6	7	8	9	10
EXTREMELY DISSATISFIED										**EXTREMELY SATISFIED**

S *12 How ***dissatisfied*** or ***satisfied*** are you with your work situation, for example, your current job, retirement for any reason, or never having worked? (*Please circle the number)*

0	1	2	3	4	5	6	7	8	9	10
EXTREMELY DISSATISFIED										**EXTREMELY SATISFIED**

S 13 How ***dissatisfied*** or ***satisfied*** are you with the kind and amount of recreation or leisure you have? (*Please circle the number)*

0	1	2	3	4	5	6	7	8	9	10
EXTREMELY DISSATISFIED										**EXTREMELY SATISFIED**

S *14 How ***dissatisfied*** or ***satisfied*** are you with your level of sexual activity or lack of sexual activity? (*Please circle the number)*

0	1	2	3	4	5	6	7	8	9	10
EXTREMELY DISSATISFIED										**EXTREMELY SATISFIED**

S *15 How ***dissatisfied*** or ***satisfied*** are you with the way your income meets your needs? (*Please circle the number)*

0	1	2	3	4	5	6	7	8	9	10
EXTREMELY DISSATISFIED										**EXTREMELY SATISFIED**

S *16 How ***dissatisfied*** or ***satisfied*** are you with how respected you are by others?
(*Please circle the number)*

0 1 2 3 4 5 6 7 8 9 10
EXTREMELY DISSATISFIED **EXTREMELY SATISFIED**

S *17 How ***dissatisfied*** or ***satisfied*** are you with the meaning and purpose of your life?
(*Please circle the number)*

0 1 2 3 4 5 6 7 8 9 10
EXTREMELY DISSATISFIED **EXTREMELY SATISFIED**

S 18 How ***dissatisfied*** or ***satisfied*** are you with the amount of variety in your life?
(*Please circle the number)*

0 1 2 3 4 5 6 7 8 9 10
EXTREMELY DISSATISFIED **EXTREMELY SATISFIED**

P 19 How ***dissatisfied*** or ***satisfied*** are you with the amount and kind of sleep you get?
(*Please circle the number)*

0 1 2 3 4 5 6 7 8 9 10
EXTREMELY DISSATISFIED **EXTREMELY SATISFIED**

THE FOLLOWING ITEM IS ADMINISTERED WITH THE PQoL AND CAN BE USED FOR CONVERGENT VALIDITY IN COMPARISON WITH THE OVERALL PQoL SCORE

S *20 How happy are you? (*Please circle the number*)

0 1 2 3 4 5 6 7 8 9 10
EXTREMELY UNHAPPY **EXTREMELY HAPPY**

**Indicates items from original 12-item version*

Scoring Instructions and Scale Characteristics:

Nineteen item scores and an overall score based on the mean or median of the 19 item scores can be constructed. Internal consistency (Cronbach's Alpha) for the original 12 item PQoL scale is 0.88 or above for both ill and well older adults. In a study of patients with chronic obstructive pulmonary disease, the internal consistency of the 19 item PQoL was examined in 90 respondents. (Guttman-Cronbach alpha = 0.91), with a range of corrected item-total correlations from 0.33 on the sleep item to 0.71 on the work/current retirement item. Most respondents, including older adults express a moderate to high level of satisfaction. A population mean\median of 7.5 has been observed (N=3359). Interpretation of the measure in cross-sectional use is Dissatisfied is a score <7.5 and Satisfied is a score >7.5.

Measurement model\Domain Structure: A factor analyses of the 19-item PQoL were conducted on data obtained from 2500 well older adults participating in a health promotion/disease prevention project conducted by the University of Washington and Group Health Cooperative of Puget Sound. These analyses, conducted using the "PROMAX" rotation in *SAS,* resulted in three factors labeled as follows:

P = Satisfaction with physical health and well-being
S = Satisfaction with social health and well-being
C = Satisfaction with cognitive health and well-being

Item 7 did not appear to fall into any factor and is best to use on its own. Subscale scores for satisfaction with physical, social, and cognitive health can be used in analyses as well as overall score. Item-response analyses are currently being conducted to confirm these scores and domain structure.

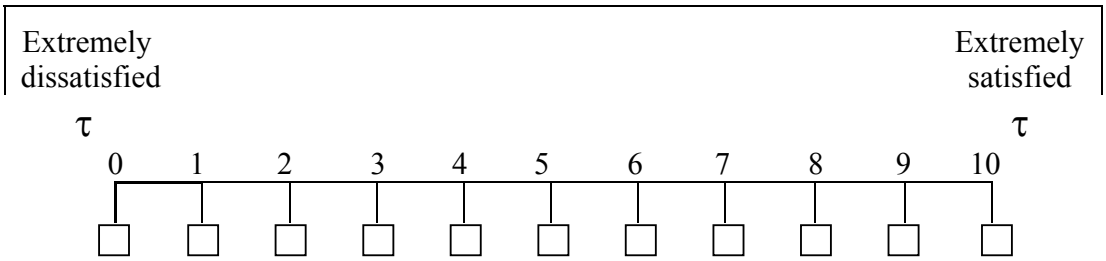
For convergent validity, the overall PQoL score can be correlated with Item 20, the happiness rating. The Pearson’s or ICC correlation coefficient should exceed 0.70.

Satisfaction with Health and Life

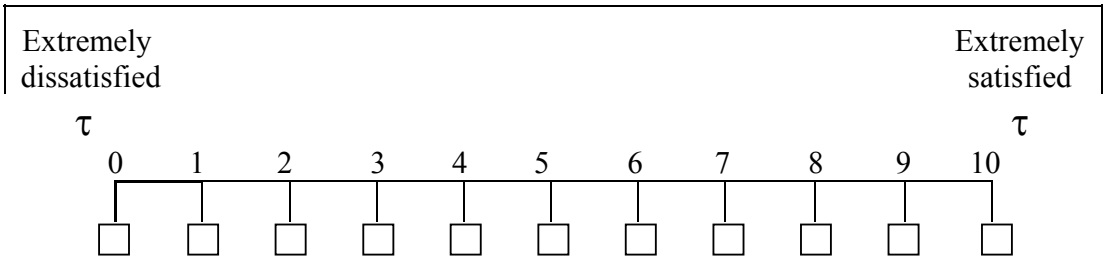
We would like to know how satisfied you are with different aspects of your life. Each item below has a scale where "0" is Extremely Dissatisfied and "10" is Extremely Satisfied. [For each item, mark an ☒ in the box of the number that shows your own level of satisfaction.]

How dissatisfied or satisfied are you with:

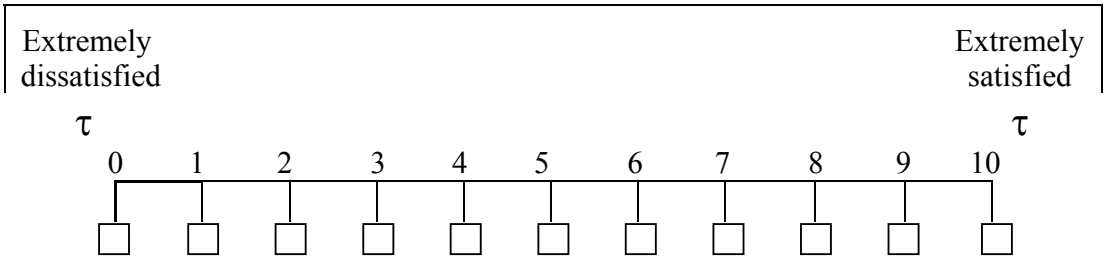
1 Your physical health (the health of your body)?



2 How well you care for yourself, for example, preparing meals, bathing, or shopping?



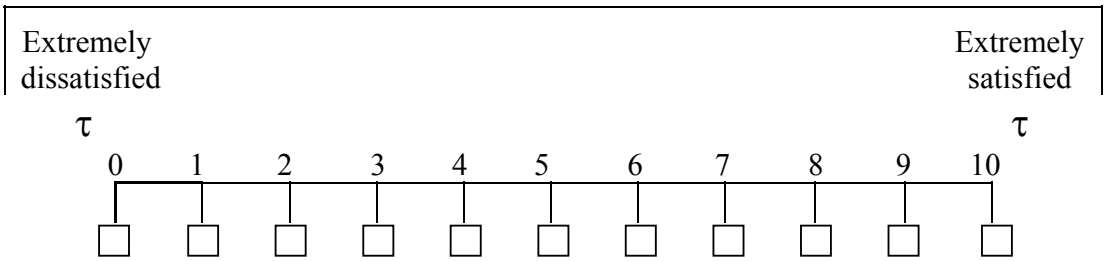
3 How well you think and remember?



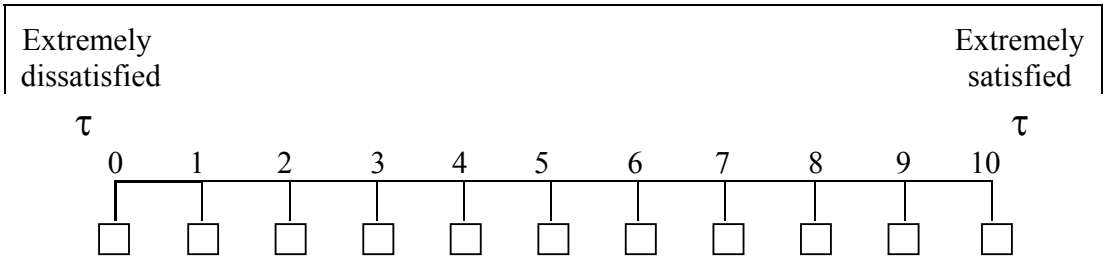
(Please turn the page)

How dissatisfied or satisfied are you with:

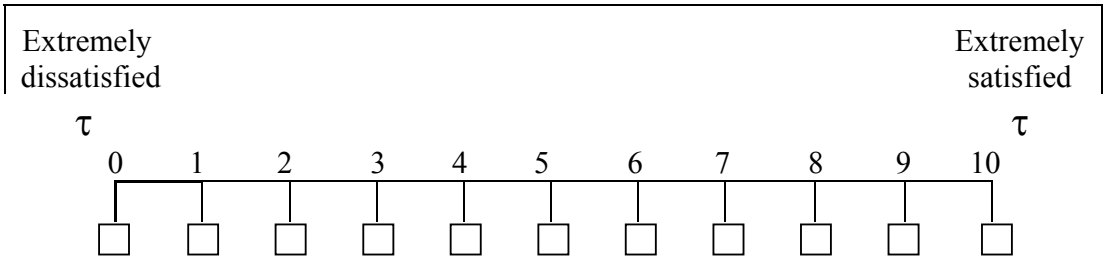
4 The amount of walking you do?



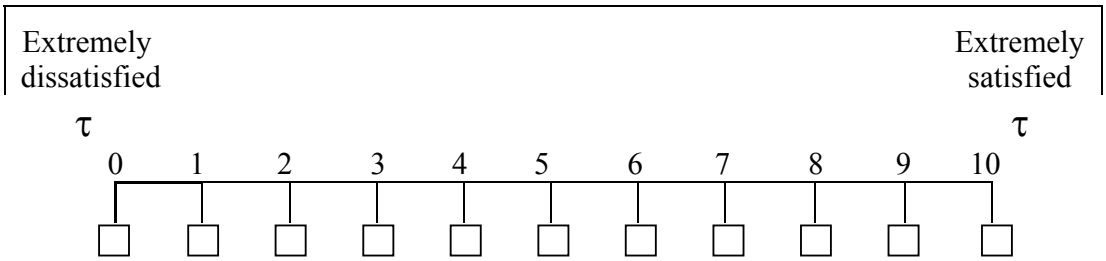
5 How often you get outside the house, for example, going into town, using public transportation or driving?



6 How well you carry on a conversation, for example, speaking clearly, hearing others, or being understood?



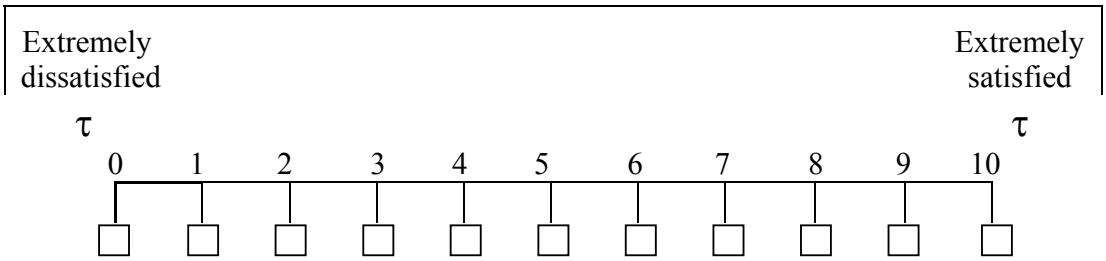
7 The kind and amount of food you eat?



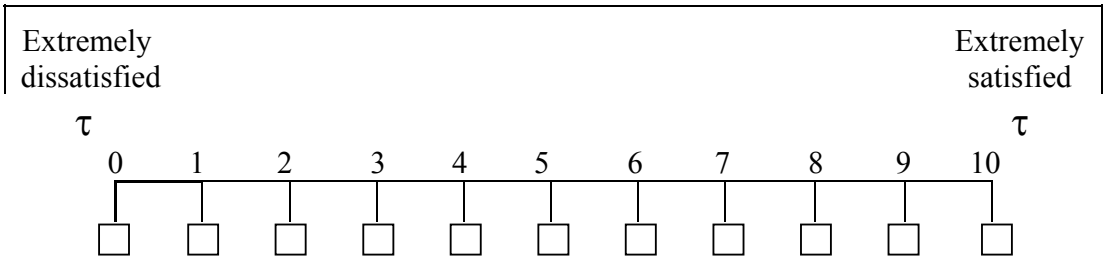
(Please turn the page)

How dissatisfied or satisfied are you with:

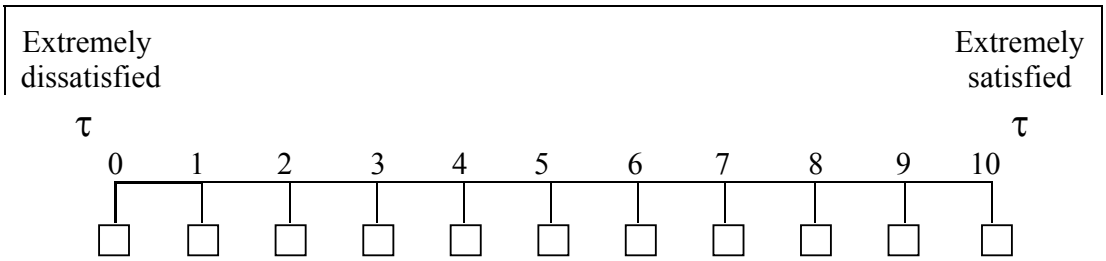
8 How often you see or talk to your family and friends?



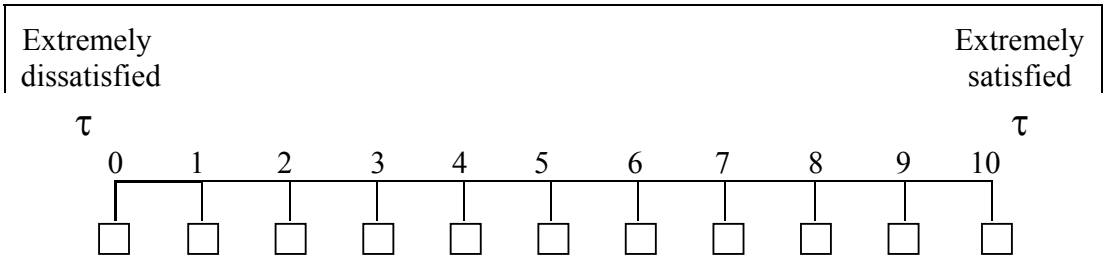
9 The help you get from your family and friends, for example, helping in an emergency, fixing your house, or doing errands?



10 The help you give to your family and friends?



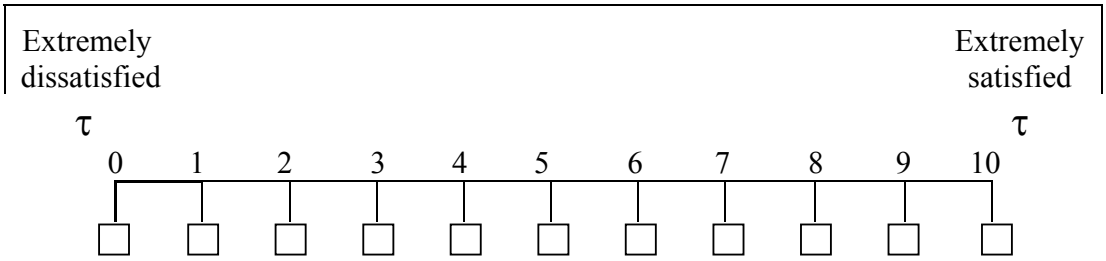
11 Your contribution to your community, for example, a neighborhood, religious, political or other group?



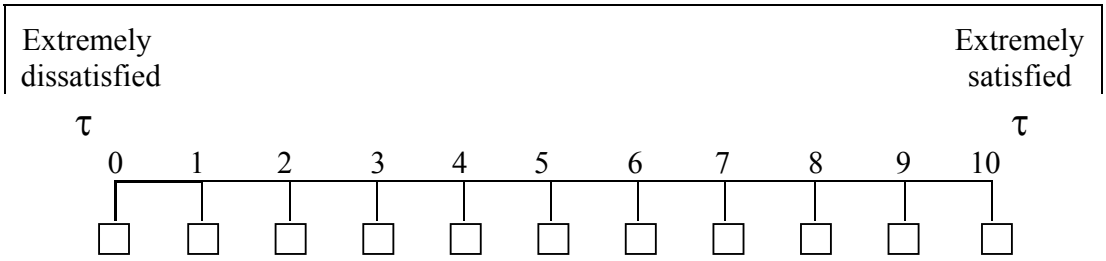
(Please turn the page)

How dissatisfied or satisfied are you with:

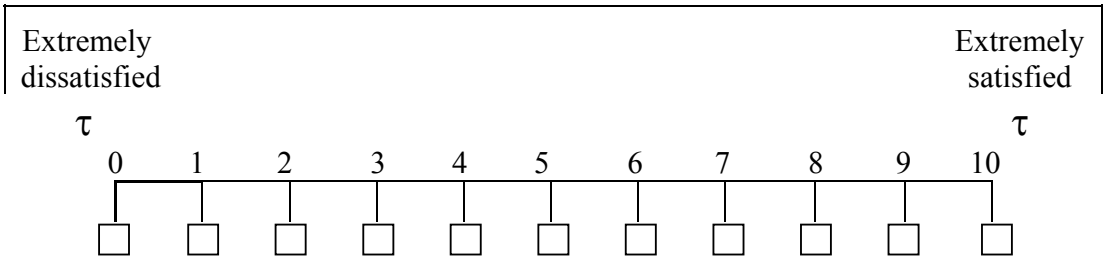
12 Your retirement or current job?



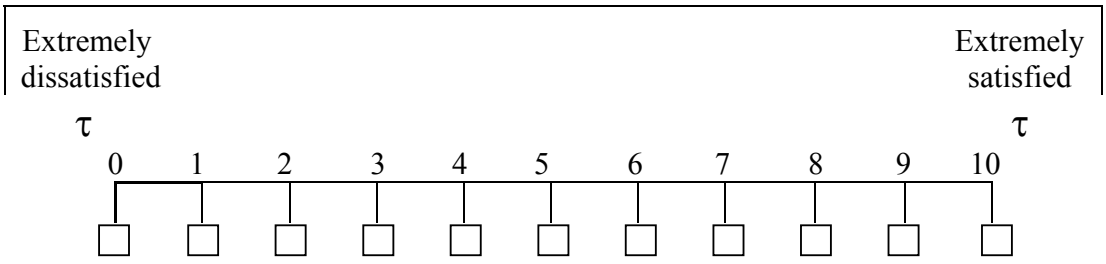
13 The kind and amount of recreation or leisure you have?



14 Your level of sexual activity or lack of sexual activity?



15 The way your income meets your needs?



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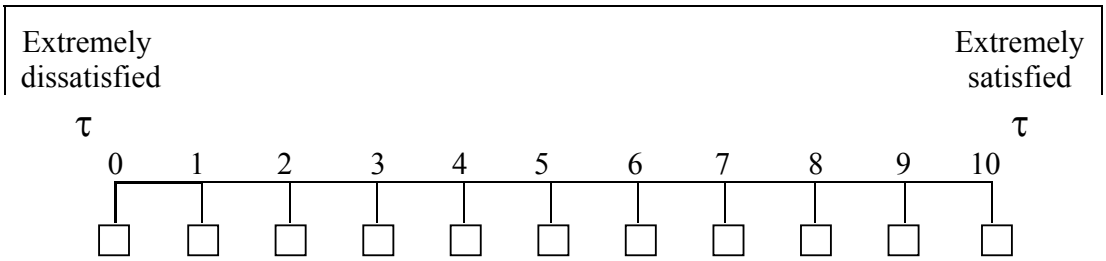
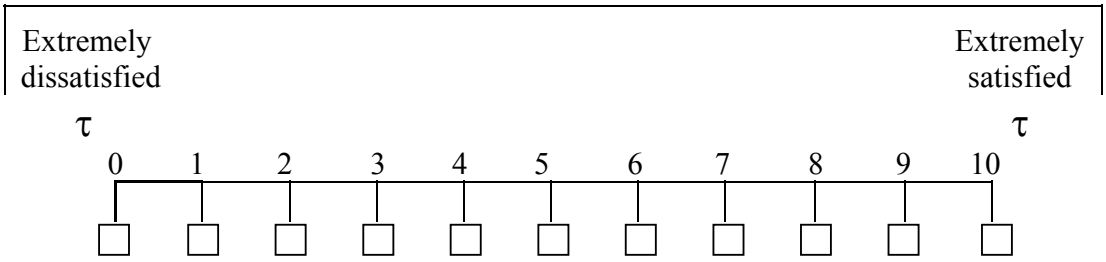
How dissatisfied or satisfied are you with:

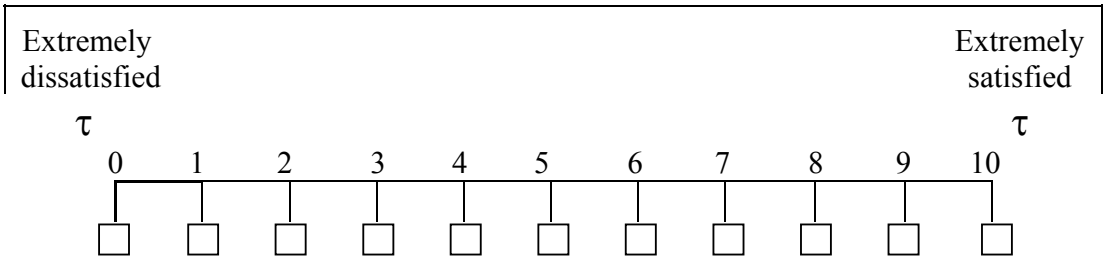
16 How respected you are by others?



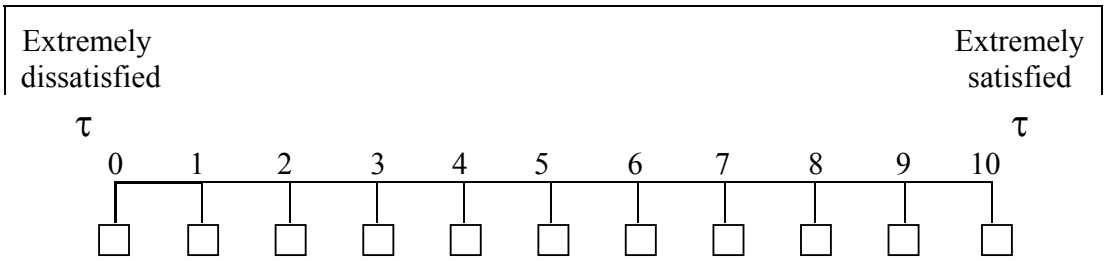
17 The meaning and purpose of your life?



18 The amount of variety in your life?



19 The amount and kind of sleep you get?



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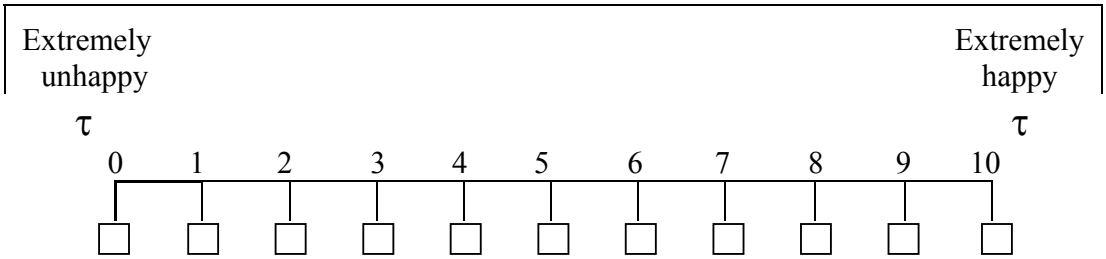
20 How happy are you?



PICTURED CHILD'S QUALITY OF LIFE SELF QUESTIONNAIRE

Pictured Child's Quality of Life Self Questionnaire was developed by Sabine Manificat, and Alice Dazord in French. The purpose of this questionnaire is to assess the child's subjective Quality of Life. The mode of administiration of this instrument is by the participant his/herself. It is 26 items for 3 to 5 years old children, and 33 items for 6 to 11 years old children.

Abbreviated Name: AUQUEI (Autoquestionnaire de qualité de vie enfant imagé)
Author(s): Sabine Manificat, Alice Dazord
Purpose: To assess the child's subjective Quality of Life
Population: Pediatrics
Age Range: 4-12 years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-administered
Time required:	10-15 minutes
Response Options:	Likert scale
Scoring:	Global score Scores by dimension Satisfaction is quoted on a four point scale, from 0 to 3. A global score is obtained from the mean of all items
Score Direction:	Higher scores show better QoL

Number of Items:
3 to 5 years old children: 26
6 to 11 years old children: 33
Original Language: French
Existing Translations: English, German, Italian, Portuguese, Spanish

Contact for information and permission to use:

Dr Sabine Manificat
Script-Inserm
290, route de Vienne
Hôpital St Jean de Dieu
69008 Lyon, France
Phone: +33 (0)4 37 90 12 96
Fax: +33 (0)4 37 90 10 00

Dimensions covered by the questionnaire :

- Family life and relations
- External activities (schooling, sport)
- Leisure activities
- Self image
- Separation situation
- Major function
- Social relation
- Treatment situation

Key References:

1. Manificat S, Dazord A. (Evaluation of the Child's Quality of Life: Validation of a Questionnaire and First Results) [In French] Evaluation de la qualité de vie de l'enfant : validation d'un questionnaire, premiers résultats. Expansion Scientifique Française 1997;45(3):106-114

2. Garcia E, Gonzales MP, Saiz PA et al. The Spanish version of the AUQUEI questionnaire (child pictured self report). 5th Annual Conference of the International Society for Quality of Life Research. Quality of Life Research 1998;7:597

A Spanish adaptation and validation of a French questionnaire, the AUQUEI, for assessing quality of life in children was made. A total of 198 children were interviewed: 133 healthy children [mean age 8.9 (SD 1), 51.9% males], 30 children with haematological cancer [mean age 11 (SD 3.2), 56.7% males], and 35 children with asthma [mean age 9.5 (SD 2.9), 62.5% males]. Translation phase: a group of 3 people made the initial translation and a back-translation was made by a bilingual person. Feasability: a good response rate was obtained: 92.1%. Only 2 patients refused to answer the questionnaire (both of these from the haematological group) and 14 children were too young to answer (under 4 yrs of age). Items with the greatest rate of non-response were: “when playing with their brothers or sisters” (45 cases), “when thinking of their father” (11 cases), “when receiving their marks” (3 cases) and when “they meet their grandparents” (3 cases). Reliability: the internal consistency (Cronbach’s alpha) was moderate = 0.6351. Construct validity: factor analysis (extraction method: principal axis factoring): 4 factors explain 27.9% of the variance. Factor 1 (functions) explains 11.9%, factor 2 (autonomy-hospital) explains 6.8%, factor 3 (leisure) explains 5.5%, and factor 4 (family) explains 3.7% of the variance. The psychometric properties of the Spanish version of the AUQUEI can be considered as moderate. Further investigation with a large sample is needed.

Questionnaire AUQUEI

Quand tu vas chez le docteur,
dis comment tu es ?

Figure 1

Questionnaire AUQUEI
Première page

Quelquefois tu n'es pas content du tout	Quelquefois tu n'es pas content	Quelquefois tu es content	Quelquefois tu es très content
Dis pourquoi :	Dis pourquoi :	Dis pourquoi :	Dis pourquoi : .....

réponses ouvertes des enfants

Mécontentement

- Papa m'a envoyé dans ma chambre parce que j'ai fait quelque chose de mal et après je boude
- Maman confond les prénoms
- Quand maman pleure, elle fait une dépression à cause de moi
- Parce que je pense à mes parents qui sont divorcés
- Je reçois des baffes
- Quand je veux des pâtes et que ma mère me donne du riz
- On m'offre toujours des habits et très peu de jouets.
- La maîtresse m'énerve avec ses maths.
- Quand on me met un gilet vert
- Parce que je dois toujours faire la sieste
- Quand j'ai une mauvaise créantinine ou une mauvaise note
- Quand on se moque de ma taille ou parce que j'ai des poils
- Quand je suis toute seule dans le noir
- On ne m'aime pas
- La petite fille d'à côté ne veut pas jouer avec moi
- C'est moi qui prend à la place des autres
- On m'a volé mon goûter
- J'ai pas d'amis

Contentement

- Maman me fait des câlins
- Je fais des maquettes avec Papa
- Maman m'amène voir Papa
- Parce que j'ai attendu longtemps et j'ai enfin quelque chose que j'attendais
- J'ai réussi à faire quelque chose de dur
- Quand j'ai une gommette verte
- Il y a pas d'école
- J'organise des spectacles
- Je fais ce que je veux
- Quand je regarde des films de guerre
- Quand j'ai appris le premier doigt de l'alto
- On va à Wallibi
- On me met de la pommade avant de piquer
- Que je sois en vie
- Quand je pense aux animaux
- Je m'amuse sans me disputer
- Ma copine vient dormir chez moi
- Je suis avec beaucoup de gens gentils

SOMETIMES YOU ARE NOT HAPPY, WHY ?
I am alone in the dark (3 years)
Because I want to watch TV and my mother says no (3 years)
I have to wear my green jacket (4 years)
I don't know what to play (5 years)
My mother died (6 years)
Because I lost something (6 years)
Because someone betrayed me (8 years)
When my brother takes all the food I want (9 years)
When I don't succeed in doing something (11 years)
I got a bad creatinin or a bad mark (12 years)
I get face slapped (9 years)
I always receive clothes and very few toys (6 years)

SOMETIMES YOU ARE HAPPY, WHY ?
Because the nurse didn't hurt me (4 years)
My mother shows me something (5 years)
I made some friends (7 years)
Because I received a gift (7 years)
Because I know what to do (8 years)
Because no one bothers me any more (8 years)
Because I heard some good news (10 years)
Because I waited for a long time and finally got what I wanted (10 years)
When I'm successful in something (11 years)
When Mummy says that I drow well (4 years)

THE DIFFERENCES BETWEEN THE FACES ARE USUALLY QUITE WELL UNDERSTOOD:
Sometimes you are happy, why ?
When I can invite ONE friend.
Sometimes you are very happy, why ?
When I can invite SEVERAL friends.

PSYCHOSOCIAL IMPACT OF ASSISTIVE DEVICES SCALE

The Psychosocial Impact of Assistive Devices Scale (PIADS) is a 26-item, self-rating questionnaire designed to measure user perceptions of how assistive devices affect quality of life. It is intended to be a generic measure, applicable to virtually all forms of AT. The PIADS describes user perceptions along three dimensions: Adaptability (the enabling and liberating effects of a device); Competence (the impacts of a device on functional independence, performance and productivity); and Self-esteem (the extent to which a device has affected self-confidence, self-esteem and emotional well being). Scores can range from –3 (maximum negative impact) through zero (no perceived impact) to +3 (maximum positive impact). The PIADS appears to be a responsive and sensitive measure of the impacts of a wide range of ATs, in populations of adults who have various forms of disability and medical condition .

Abbreviated Name: PIADS
Author(s): Cathy Sherbourne and Anita Stewart
Purpose: To measure user perceptions of how assistive devices affect quality of life
Population: Adult
Age Range : 17 to 53 years
Type of Instrument: Quality of Life & Psychological well-being
Mode of Administration:

Rater:	Self-/ Interviewer-administered
Time required:	5-10 minutes
Response Options:	Likert Scale
Scoring:	Global score
Score Direction:	Higher scores show better QoL

Number of Items: 26
Original Language: English
Existing Translations : French (Canada). Chinese and Japanese versions under development

Copyright: H. Day & J. Jutai, 1996

Contact for information and permission to use:

Erin Bloch
Department of Physical Medicine & Rehabilitation
The University of Western Ontario
St. Joseph's Health Care London
Parkwood Hospital Site
Hobbins Building, H414c
801 Commissioners Road E
London, Ontario, Canada N6C 5J1
Phone: 519-685-4292 ext. 42627
Fax: 519-685-4582
E-Mail: ebloch@piads.ca

Dimensions covered by the questionnaire :

- Adaptability: (6 items)
  - Inclination or motivation to participate socially
  - Take risks
- Competence: (12 items)
  - Functional capability
  - Independence
  - Performance
- Self-esteem: (8 items)
  - Self-confidence
  - Self-esteem
  - Emotional well-being

Key References:

1. Day, H., Jutai, J., & Campbell, K. A. (2002). Development of a scale to measure the psychosocial impact of assistive devices: lessons learned and the road ahead. Disability and Rehabilitation vol. 24, No. 1/2/3, 31-37.

PIADS
The Psychosocial Impact of Assistive Devices Scale

A Tool for Evaluating the Psychological Benefits of
Rehabilitation Technologies

MANUAL

Hy I. Day, C. Psych.
Jeffrey Jutai, Ph.D,, C. Psych.

Address correspondence to:

Jeffrey W. Jutai, Ph.D., C.Psych.
Associate Professor
Department of Physical Medicine & Rehabilitation
The University of Western Ontario
St. Joseph's Health Care London
Parkwood Hospital Site
Hobbins Building, H422
801 Commissioners Road E
London, ON N6C 5J1

Director of Applied Research
E. A. Baker Foundation of the C.N.I.B.

Tel. 519-685-4292 ext. 42626
Fax: 519-685-4582 e-mail: Jjutai@uwo.ca

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General Description of the PIADS

The PIADS is a 26-item; self-report questionnaire designed to assess the effects of an assistive device on functional independence, well-being, and quality of life. (See the sample of the PIADS Questionnaire.) The three subscales of the PIADS are based on a factor analysis of the responses combined from several studies. The first one, Competence, measures feelings of competence and efficacy. It is sensitive to the perceived impacts of assistive technology on performance and productivity. The Competence subscale (12 items) includes questions on topics such as competence, productivity, usefulness, performance, and independence. The second subscale, Adaptability (6 items), indicates a willingness to try out new things and to take risks. It is sensitive to the enabling and liberating aspects of assistive technology that might be expected if ATs enhanced "participation" as described in the WHO (ICF) framework. The Adaptability subscale includes questions on topics such as ability to participate, willingness to take chances, eagerness to try new things, and the ability to take advantage of opportunities. The third subscale, Self-esteem (6 items), indicates feelings of emotional health and happiness. It is sensitive to the perceived impact of assistive technology on self-confidence and emotional well-being. The Self-esteem subscale includes questions on topics such as self-esteem, security, sense of power and control, and self-confidence, Scores can range from -3 (maximum negative impact) through zero (no perceived impact) to +3 (maximum positive impact).

Under normal circumstances, the PIADS can be completed in 5-10 minutes. The PIADS comes with a manual that presents the conceptual basis and intended applications for the instrument, summarizes its measurement properties and validation research to date, and describes administration and scoring procedures in detail with examples. A glossary is also included to aid users in the interpretation of PIADS items where needed. The PIADS may also be used to assess a respondent's expectations of device impact (i.e., anticipated impact, prior to using the device). In this instance, there is a modified set of instructions that can be given. The PIADS can be completed reliably by telephone, although it is highly recommended that the initial assessment be done in person.

Applicability

The PIADS can be used to assess the impact of any assistive device (AD), prosthesis or medical procedure. It can be used to evaluate the impact of ADs over time and to match the devices with consumers. With its excellent psychometric properties, the PIADS fills a missing link in the assessment of Ads as well as in the examination of their acceptance and abandonment.

Administration of the PIADS

The PIADS is a self-report measure that can be easily administered individually, in a group, or via telephone. The procedure is the same whether the PIADS is administered individually or in a group, although it is important to preserve the confidentiality of the individuals during group administration. Each respondent must be provided with a pen or pencil and a flat surface to write on. Every effort must be made to ensure that the respondent is comfortable during the administration of the scale. The PIADS has been used with both children aged 10 and up and adults. Instructions for administering the PIADS by phone are included.

Respondents are told why they are completing the scale and asked to select the box that best represents how they are affected by wearing or using their device. They must be asked to respond as honestly as they can and to respond in light of how they are affected by the device as opposed to how they would like to be affected by the device. It is important that the respondents thoroughly understand the instructions. It is preferable that the test administrator be present during the administration to answer questions. (See the instructions on how to administer the PIADS from respondent and caregiver perspectives.) The PIADS may also be used to assess a respondent's expectations of device impact (i.e., anticipated impact, prior to using the device). In this instance, there is a modified set of instructions that can be given.

Scoring the Results

The PIADS Scale can be scored manually or with the aid of a computer, using an EXCEL spreadsheet. Scoring sheets are available to aid in the manual scoring process. To see an example of a completed scoring sheet, refer to Table 2. A blank scoring sheet is also included (Table 1) and distributed with the PIADS questionnaire. An electronic version of the scoring sheet can be obtained by contacting the authors.

Three PIADS subscale scores are calculated as follows:

> The Competence subscale is derived by adding the values corresponding to items 1, 3, 4, 6, 8, 11. 13, 14, 16, 17, and 18, subtracting the value corresponding to item 5 and dividing the total by 12.
>
> The Adaptability subscale is derived by adding the values corresponding to items 15, 22. 23, 24, 25, and 26 and dividing the total by 6.
>
> The Self-esteem subscale is derived by adding the values corresponding to items 2, 7, 9, 12, 19, and 20, subtracting the values corresponding to items 10 and 21 and dividing the total by 8.

Glossary of PIADS Items

Ability to Adapt to the Activities of Daily Living (item 25) Ability to cope with change; ability to make basic tasks more manageable
Ability to Participate (item 23) Ability to join in activities with other people
Ability to take advantage of opportunities (item 26) Ability to act quickly and confidently when there is a chance to improve something in your life
Adequacy (item 4) Capable of handling life situations, and handling little crises
Capability (Item 16) Feeling more capable; able to cope
Competence (item 1) Ability to do well the important things you need to do in life
Confusion (item 5) Unable to think clearly, act decisively
Eagerness to Try New Things (item 24) Feeling adventuresome and open to new experiences
Efficiency (item 6) Effective management of day to day tasks
Embarrassment (item 21) Feeling awkward or ashamed
Expertise (item 13) Knowledge in a particular area or occupation
Frustration (item 10) Being upset about lack of progress in achieving your desires; feeling disappointed
Happiness (item 2) Gladness, pleasure; satisfaction with life
Independence (item 3) not dependent on, or not always needing help from, someone or something
Performance (item 18) Able to demonstrate your skills
Productivity (item 8) Able to get more things done in a day
Quality of Life (item 17) How good your life is
Security (item 9) Feeling safe rather than feeling vulnerable or insecure
Self-Confidence (item 12) Self-reliance; trust in yourself and your abilities
Self-Esteem (item 7) how you feel about yourself, and like yourself as a person
Sense of Control (item 20) Sense of being able to do what you want in your environment
Sense of Power (item 19) Sense of inner strength; feeling that you have significant influence over your life
Skillfulness (item 14) Able to show your expertise; perform tasks well
Usefulness (item 11) Helpful to yourself and others; can get things done
Well-being (item 15) Feeling well, optimistic about your life and future
Willingness to Take Chances (item 22) willing to take some risks: willing to take on new challenges

Frequently Asked Questions

1. **How can I obtain information about the PIADS?**

Contact:

Erin Bloch
Department of Physical Medicine & Rehabilitation
The University of Western Ontario
St. Joseph's Health Care London
Parkwood Hospital Site
Hobbins Building, H414c
801 Commissioners Road E
London, Ontario, Canada N6C 5J1

Tel: 519-685-4292 ext. 42627
Fax: 519-685-4582
E-Mail: ebloch@piads.ca

- Please include your full postal address with your correspondence. We will send you our PIADS Information Package, which contains the scale, manual, reprints and other information.

2. **How do I obtain permission to use the PIADS and how much does it cost?**

- The PIADS is available free of charge for use in clinical, research or educational projects. The PIADS package includes a form for you to complete, sign and return to us. along with a brief questionnaire asking about your proposed research and how you might be using the PIADS. This process will allow you to make photocopies of the PIADS form found in the PIADS manual (Table 3)

3. **What qualifications are required to administer the PIADS?**

- No specific training is required to administer the PIADS. The form comes with a manual that presents the conceptual basis and intended applications for the instrument. The manual summarizes measurement properties and validation research to date, and describes administration and scoring procedures in detail. A glossary is also included to aid users in the interpretation of PIADS items when needed.

4. **How much time does it take to administer the PIADS?**

- Under normal circumstances, the RAIDS can be completed in 5-10 minutes.

5. **How difficult is it to administer the PIADS?**

- The PIADS is a self-report measure that can be easily administered individually, in a group, or via telephone.

6. **How difficult is it to score the PIADS?**

- Scoring the PIADS is not difficult. It can be scored manually or with the aid of a spreadsheet. Scoring sheets are available to aid in the manual scoring process. To see an example of a completed scoring sheet, refer to Table 2. A blank scoring sheet is also included in the Table 1 and distributed with the PIADS questionnaire. An electronic version of the scoring sheet can be obtained by contacting the authors. Directions for calculating the three PIADS sub-scales are found on manual pages.

7. **In what situations is the PIADS applicable?**

- The PIADS is designed to be generically applicable to any form of assistive device. It has been shown to be very sensitive to differences among device options (e.g., tilt, recline) within a device category (e.g., powered wheelchairs). Data on various combinations of user population and device category are described in the research literature. Normative data is not required to examine whether or not an assistive device has produced a positive psychosocial impact.

Need and Rationale for the PIADS

Assistive technology (AT) is designed to provide important functional benefits and improve the quality of life for people who use it. However, research has shown that people will sometimes reject or abandon what seem to be well-designed and functional devices. The possible consequences of non-use of prescribed technologies can be very serious. They include the loss of functional abilities of the user, increases in attendant and other care costs, and ineffective use of funds from provider organizations. Assistive technology might be threatening to some people and produce feelings of helplessness, frustration, and loss of control. For these reasons, designers and providers need to better understand the psychosocial factors that might determine device adoption, retention and abandonment (or discontinuance). Moreover, the field of AT needs measures that can be comfortably included in a comprehensive outcome assessment of AT.

By “psychosocial” we refer to both factors within the person and factors attributable to the environment that affect the psychological adjustment of individuals who have a disability. We are concerned with the challenges faced by these individuals in relation to the social environment. This includes measuring how they perceive their assistive devices to act as environmental facilitators, whose goal is to enhance unrestricted or facilitated participation in major areas of human life. Intrapersonal factors are the core dimensions of psychological well-being, which include independence, personal control, self-efficacy, and self-acceptance. In our experience, they are essential components of how AT users define the impact of their devices on their quality of life.

Investigating the psychosocial impact of an AT on its user may shed some light into the reasons for its use and abandonment. It may also make it possible to address the problematic areas of an AT, leading to the design of improved devices and related services. However, the psychosocial constructs that may be crucial to the satisfaction of the user have not yet been operationalized or assessed. Assistive device designers and service providers need to better understand the psychosocial factors that might determine device adoption and retention and discontinuance outcomes.

Why not use a so-called health-related quality of life (QOL) measure? A number of published generic and disease-specific "quality of life" measurement scales might be considered for use in assessing AT impact. They have two primary limitations. First, they are too medically oriented. Most assistive devices are not intended to promote health and healing, but rather to improve or restore functional capabilities. Second, they are designed to assess health status or change in health status and not the impact attributable to any particular form of intervention. They are either not sensitive enough to detect functional and psychosocial changes specific to an AT intervention, or cannot be used with some clients because their functional limitations, although accommodated through AT, are too severe to permit reliable assessment using the instrument. In any event, AT is meant to achieve different QOL outcomes than surgery, physical therapy, and pharmaceutical treatments.

The Psychosocial Impact of Assistive Devices Scale (PIADS) was researched and developed to fill the need for a reliable, valid, and economical measure that is generically applicable across all major categories of assistive technology.

Development of the PIADS

PIADS items were created from 3 principal sources: (1) empirical explorations with the Pleasure-Arousal-Dominance scale; (2) qualitative research (focus groups) wherein AT users were asked to describe how they expected devices to impact their quality of life; (3) the literature on personality research which suggested that the PIADS include items that are associated with constructs such as perceived self-efficacy and personal control. The priority was to create a scale that would reliably measure perceived device impact and discriminate among device categories and user conditions in a clinically sensible way. The authors were less concerned originally about developing a measure that was consistent with any single theoretical perspective.

Nonetheless, the PIADS embodies assumptions about QOL that are consistent with emerging, influential frameworks in disability and rehabilitation research. Principally, QOL is a complex and multidimensional construct. It is dynamic, changing over time and over a person's life. It arises from a person's interaction with their environment. It is experienced differently from person to person, but has the same components for everyone. The most important perspective on how an AT affects quality of life is the perspective of the device user. We defined quality of life impact following Renwick, Brown & Raphael as the effect of the device on, "the degree to which a person enjoys the important possibilities of his/her life". An assistive device should promote good quality of life for the user to the extent to which it makes the user feel competent, confident, and inclined (or motivated) to exploit life's possibilities, These three key dimensions have been determined empirically to underlie how users perceive the psychosocial impact of an AT

Psychometric Properties of the PIADS

The psychometric qualities of the PIADS have been described in a number of publications as being good to excellent. The results are summarized in Table.

Table Psychometric properties of the PIADS

Reference	Internal consistency	Test-retest reliability	Stability	Reliability of caregiver proxy	Sensitivity to user condition and device features	Responsive-ness to device intervention	Validity
6, 14	√	√	√				√
12, 23					√	√	√
17	√	√	√				
24				√			
20, 25					√		√
18			√				
19	√	√					√
21			√			√	√

Day and Jutai described the basic psychometric properties of the PIADS, based on a sample of eyewear devices users (n=307). Internal consistency was assessed using Cronbach's alpha. Values

were .95 for the PIADS total score and .92, .88, and .87 for the Competence, Adaptability, and Self-esteem subscales, respectively. Sixty respondents completed the PIADS twice, about a month apart. None of the f tests comparing the two assessments reached significant differences (p values ranging from .77 to .85), indicating the stability of the scale. Construct validity was examined using a Principal Component Analysis of the data from 307 subjects. The results yielded three distinct subscales, accounting for 61.1% of the total variance. This 3-dimensional structure was confirmed in replication studies involving 150 eyewear device users and 92 wheelchair users. Construct validity was further demonstrated in an examination of the association of the PIADS with a measure believed to tap environmental impact on emotional responses: the Pleasure, Dominance and Arousal (PAD) scale. The Pearson correlation coefficients (rp) were significant at the 0.05 level between the PIADS subscales and the Pleasure (rp .46 to .59) and Dominance subscales (rp .21 to .34) but not with the Arousal subscale (rp .06 to .17). The results were interpreted as supporting the discriminant validity of the PIADS.

Validity was further supported by a study of the scale's ability to distinguish the responses from eyeglass wearers and contact lens wearers, in which group patterns of response were consistent with predictions from the literature. Demers and colleagues found that both the three subscales and total scale of the French translation of the PIADS had good test-retest reliability (ICC of .77 to .90) and internal consistency (.75 to .94). Concurrent validity with the source (original, English) PIADS also produced acceptable coefficients (.77 to .83). Comparisons between PIADS scores and qualitative data obtained through interviews with device users indicate a high degree of reflection of user concerns and issues in the PIADS. User expectations of psychosocial impact from device use accurately predict their experiences following device adoption.

The studies summarized in the Table have demonstrated that the PIADS is a reliable, valid, and responsive measure, with good clinical utility. The PIADS is a sensitive measure of the impact of a wide range of ATs, in populations of adults who have various forms of disability and medical condition. Highlights from the research findings to date include:

- The psychosocial impact of assistive devices can be reliably assessed in a standardized way across diverse populations of device users.
- The PIADS is capable of predicting device retention and abandonment.
- Patterns of psychosocial impact vary across populations of device users.
- Devices associated with stigma produce predictable patterns of psychosocial response.
- The psychosocial impact of assistive devices is dissociable from the effects of illness and disabling condition.
- The overall agreement between user self-report and caregiver report of device impact on the user is surprisingly good.
- The PIADS is sensitive to clinically and functionally important variables associated with the user's condition and device capabilibes.

Other projects are currently underway to: (1) develop versions of the PIADS suitable for young children and for adults who have cognitive difficulties; (2) examine the validity of translations of the PIADS into languages other than English; (3) investigate psychosocial factors in the long-

term device use and discontinuance for various populations of device users. At present, the only translated version of the PIADS is Canadian French.

The ability of the PIADS to predict abandonment and retention has prompted examination of how the PIADS can best be used to advance the knowledge base in this area. Theories thus far considered include personal control and self-efficacy. They are possibly the most promising psychological conceptualizations for developing a user-focused, environmentally sensitive understanding of AT adoption and retention. When AT is successful in helping people maintain or regain control, important results are increased self-efficacy and decreased negative emotional reactions to disability. These effects in turn are hypothesized to enhance subjective well-being. They are forms of psychosocial impact that are measured in the PIADS.

The PIADS is a reliable and valid tool that appears to have significant power to predict important AT outcomes. It can and should be used both deductively and inductively to build and test theory about the psychosocial impact of assistive technology. Further investigation is needed into the relationships among the PIADS and other validated outcome measures. Researchers are encouraged to keep the PIADS, authors informed about their findings (see contact information page).

Table 1: PIADS Scoring Sheet

PIADS SCORING SHEET

Client ID#: Device:

Item	Competence	Adaptability	Self-Esteem
1. Competence	1.		
2. Happiness			2.
3. Independence	3.		
4. Adequacy	4.		
5. ***Confusion****	5.*		
6. Efficiency	6.		
7. Self-esteem			7.
8. Productivity	8.		
9. Security			9.
10. ***Frustration****			10.*
11. Usefulness	11.		
12. Self-confidence			12.
13. Expertise	13.		
14. Skillfulness	14.		
15. Well-being		15.	
16. Capability	16.		
17. Quality of life	17.		
18. Performance	18.		
19. Sense of power			19.
20. Sense of control			20.
21. ***Embarrassment****			21.*
22. Willingness to take chances		22.	
23. Ability to participate		23.	
24. Eagerness to try new things		24.	
25. Ability to adapt to the activities of daily living		25.	
26. Ability to take advantage of opportunities		26.	
(A) Sum of subscale column			
(B) Number of items in subscale	12	6	8
SUBSCALE SCORE (A) ÷ (B)			

* Note: A high positive score on any of these three items (5, 10 and 21) would indicate a ***negative*** impact on quality of life. (For all other items, a high positive score indicates a positive impact on the quality of life.) To capture the meaning of the scores for items 5, 10 and 21, the sign of the respondent's score must be reversed. For example, a respondent who chose a value of (-2) for item 5 would be indicating that the device had diminished their level of frustration. This diminished level of frustration would have a positive impact on quality of life. To reflect that positive impact the (-2) would be changed to a (+2) on this scoring sheet.

August 2, 2000

Table 2: Completed Sample of PIADS Scoring Sheet

PIADS SCORING SHEET

Client ID#: 95876 Device: Walker

Item	Competence	Adaptability	Self-Esteem
1. Competence	1. 2		
2. Happiness			2. 2
3. Independence	3. 3		
4. Adequacy	4. 2		
5. ***Confusion****	5.* (-1)= 1		
6. Efficiency	6. 2		
7. Self-esteem			7. 3
8. Productivity	8. 3		
9. Security			9. 2
10. ***Frustration****			10.* (-2) = 2
11. Usefulness	11. 2		
12. Self-confidence			12. 3
13. Expertise	13. 2		
14. Skillfulness	14. 2		
15. Well-being		15. 3	
16. Capability	16. 3		
17. Quality of life	17. 3		
18. Performance	18. 3		
19. Sense of power			19. 1
20. Sense of control			20. 2
21. ***Embarrassment****			21.* (-3) = 3
22. Willingness to take chances		22. -2	
23. Ability to participate		23. 2	
24. Eagerness to try new things		24. 2	
25. Ability to adapt to the activities of daily living		25. 2	
26. Ability to take advantage of opportunities		26. 3	
(A) Sum of subscale column	28	10	18
(B) Number of items in subscale	12	6	8
SUBSCALE SCORE (A) ÷ (B)	2.33	1.67	2.25

* Note: A high positive score on any of these three items (5, 10 and 21) would indicate a ***negative*** impact on quality of life. (For all other items, a high positive score indicates a positive impact on the quality of life.) To capture the meaning of the scores for items 5, 10 and 21, the sign of the respondent's score must be reversed. For example, a respondent who chose a value of (-2) for item 5 would be indicating that the device had diminished their level of frustration. This diminished level of frustration would have a positive impact on quality of life. To reflect that positive impact the (-2) would be changed to a (+2) on this scoring sheet.

Table 3: PIADS Questionnaire Version 3.0

Psychosocial Impact of Assistive Devices Scale (PIADS) **Today's Date:** _____
month/day/year

Client Name:_____ ☐ male ☐ female
(last name, then first name)

Diagnosis:_____ Date of Birth:_____
month/day/year

The form is being filled out at (choose one) **1.** ☐ home **2.** ☐ a clinic **3.** ☐ other (describe):_____

The form is being filled out by (choose one) **1.** ☐ the client, without any help **2.** ☐ the client, with help from the caregiver (e.g., client showed or told caregiver what answers to give) **3.** ☐ the caregiver on behalf of the client, without any direction from the client **4.** ☐ other (describe): _____

Each word or phrase below describes how using an assistive device may affect a user. Some might seem unusual but it is important that you answer every one of the 26 items. So, for each word or phrase, put an "X" in the appropriate box to show how you are affected by using the _____ (device name).

	Decreases	-3	-2	-1	0	1	2	3	Increases
1)	competence	☐	☐	☐	☐	☐	☐	☐	
2)	happiness	☐	☐	☐	☐	☐	☐	☐	
3)	independence	☐	☐	☐	☐	☐	☐	☐	
4)	adequacy	☐	☐	☐	☐	☐	☐	☐	
5)	confusion	☐	☐	☐	☐	☐	☐	☐	
6)	efficiency	☐	☐	☐	☐	☐	☐	☐	
7)	self-esteem	☐	☐	☐	☐	☐	☐	☐	
8)	productivity	☐	☐	☐	☐	☐	☐	☐	
9)	security	☐	☐	☐	☐	☐	☐	☐	
10)	frustration	☐	☐	☐	☐	☐	☐	☐	
11)	usefulness	☐	☐	☐	☐	☐	☐	☐	
12)	self-confidence	☐	☐	☐	☐	☐	☐	☐	
13)	expertise	☐	☐	☐	☐	☐	☐	☐	
14)	skillfulness	☐	☐	☐	☐	☐	☐	☐	
15)	well-being	☐	☐	☐	☐	☐	☐	☐	
16)	capability	☐	☐	☐	☐	☐	☐	☐	
17)	quality of life	☐	☐	☐	☐	☐	☐	☐	
18)	performance	☐	☐	☐	☐	☐	☐	☐	
19)	sense of power	☐	☐	☐	☐	☐	☐	☐	
20)	sense of control	☐	☐	☐	☐	☐	☐	☐	
21)	embarrassment	☐	☐	☐	☐	☐	☐	☐	
22)	willingness to take chances	☐	☐	☐	☐	☐	☐	☐	
23)	ability to participate	☐	☐	☐	☐	☐	☐	☐	
24)	eagerness to try new things	☐	☐	☐	☐	☐	☐	☐	
25)	ability to adapt to the activities of daily living	☐	☐	☐	☐	☐	☐	☐	
26)	ability to take advantage of opportunities	☐	☐	☐	☐	☐	☐	☐	

Instructions on Completing the PIADS: Client Version

When instructing a client on how to complete the PIADS, stick as closely as possible to the script given below. Do not define the words and phrases that make up the PIADS items unless the client asks for help.

If the client is not sure how the item applies, tell him/her that if he/she cannot decide whether the assistive device has had a positive or negative effect with regard to that word or phrase, then he/she should put a mark in the "0" box, to indicate no effect.

Be sure the client understands that every item on the PIADS must be answered. There is no 'Not Applicable' option. Also, check to see that the client is not responding randomly or giving the same response to each item without sufficient consideration.

If the client asks for a definition for a PIADS item, give the explanation for the item that is in the PIADS glossary. Remind the client that there are no right or wrong answers on the PIADS, and that every item must be answered. The PIADS is all about how he/she feels about each item, and how he/she interprets it in terms of his/her own life and experiences. It after you have gone through this explanation the client is still puzzled by an item, encourage him/her to take a guess, and move on to the next item. (Note that the PIADS need not be completed in order of the number beside each item. If the client wants to, he/she can skip an item and come back to it later, so long as all items are answered.)

1. The PIADS Impact Scale is a questionnaire that asks you to describe how an assistive device (give an example appropriate to the client, e.g., wheelchair) affects your life and makes you feel.
2. For each word or phrase, put a mark in the box that best describes your feelings. Mark only one box for each word or phrase, and do not put a mark between boxes.
3. Let's look at a couple of examples of how the questionnaire works when you are describing your feelings about one of the words or phrases. Let's look at how you might rate your reactions to the word, "competence".
4. If the device has helped you to feel very much more competent than you feel without it (or before you started using it), put a mark in the "3" box.
5. If the device has helped you to feel somewhat more competent, but not as competent as you thought you might feel, you might put a mark in either the "1" box or the "2" box.
6. If the device has not made you feel any more or less competent, put a mark in the "0" box.
7. If the device has made you feel quite incompetent (or a lot less competent than you used to feel), then put a mark in the "-3' box.
8. If the device has made you feel somewhat incompetent (or less competent than you used to feel), then you might put a mark in either the '-2" box or the "-1" box.

Additional Notes for Using the PIADS with Clients who have Degenerative Disorders or Traumatic Injuries

If the client appears to be stuck or non-committal, you should try to give encouragement as a means of moving the interview along. This might entail suggesting examples suited to the client's device and personal experiences. For example, for the item, Efficiency, you might ask the client to consider whether writing letters is important to him/her, and if so, has a writing aid helped him/her to write letters more efficiently than when he/she did not have the device.

Be prepared for resistance from a client or caregiver. Resistance and agitation may arise from their emotional response to the client's diagnosis or prognosis.

Resistance might also result from the number of device questionnaires needed to be filled out, in cases where a client uses more than one device. Exercise good judgment, and be sensitive to the client's level of fatigue, when administering more than one PIADS in a single session. Where possible, allow for short rest periods between assessments. Be patient, and help the client maintain focus when filling out the PIADS, as sometimes the PIADS might prompt an off-topic discussion.

Instructions on Completing the PIADS: Caregiver Version

When instructing a caregiver on how to complete the PIADS on behalf of a client, stick as closely as possible to the script given below. Do not define the words and phrases which makeup the PIADS items unless the caregiver asks for help.

If the caregiver is not sure how the item applies, tell him/her that if he/she cannot decide whether the assistive device has had a positive or negative effect with regard to that word or phrase, then he/she should put a mark in the "0" box, to indicate no effect.

Be sure the client understands that every item on the PIADS must be answered. There is no "Not Applicable" option. Also, check to see that the caregiver is not responding randomly or giving the same response to each item without sufficient consideration.

If the caregiver asks for a definition for a PIADS item, give the explanation for the item which is in the PIADS glossary. Remind the caregiver that there are no right or wrong answers on the PIADS, and that every item must be answered. The PIADS is all about how he/she feels about each item, and how he/she interprets it in terms of the client's life and experiences. If after you have gone through this explanation the caregiver is still puzzled by an item, encourage him/her to take a guess, and move on to the next item. (Note that the PIADS need not be completed in order of the number beside each item. If the caregiver wants to, he/she can skip an item and come back to it later, so long as all items are answered.)

1. The PIADS Impact Scale is a questionnaire that asks you to describe how an assistive device (give an example appropriate to the caregiver, e.g., wheelchair) affects the life of the person you are raring for and makes that person feel.

2. For each word or phrase, put a mark in the box that best describes these feelings. Mark only one box for each word or phrase, and do not put a mark between boxes.
3. Let's look at a couple of examples of how the questionnaire works when you are describing the client's feelings about one of the words or phrases. Let's look at how you might rate his/her reactions to the word, “competence”.
4. If the device has helped him/her to feel very much more competent than he/she feels without it (or before he/she started using it), put a mark in the “3” box.
5. If the device has helped him/her to feel somewhat more competent, but not as competent as you thought he/she might feel, you might put a mark in either the "1" box or the “2” box.
6. If the device has not made him/her feel any more or less competent, put a mark in the “0” box.
7. If the device has made him/her feel quite incompetent (or a lot less competent than he/she used to feel), then put a mark in the “-3” box.
8. If the device has made him/her feel somewhat incompetent (or less competent than he/she used to feel), then you might put a mark in either the “-2” box or the “-1” box.

Additional Notes for Using the PIADS with Clients who have Degenerative Disorders or Traumatic Injuries

If the caregiver appears to be stuck or non-committal, you should try to give encouragement as a means of moving the interview along. This might entail suggesting examples suited to the client's device and personal experiences. For example, for the item, Efficiency, you might ask the caregiver to consider whether writing letters is important to the client, and if so, has a writing aid helped the client to write letters more efficiently than when he/she did not have the device.

Be prepared for resistance from a client or caregiver. Resistance and agitation may arise from their emotional response to the client's diagnosis or prognosis.

Resistance might also result from the number of device questionnaires needed to be filled out, in cases where a client uses more than one device. Exercise good judgment, and be sensitive to the caregiver’s level of fatigue, when administering more than one PIADS in a single session. Where possible, allow for short rest periods between assessments. Be patient, and help the caregiver maintain focus when filling out the PIADS, as sometimes the PIADS might prompt an off-topic discussion.

Instructions on Completing the PIADS with A Caregiver for a Client who has Recently Passed Away

See manual, "Instructions on Completing the PIADS: Caregiver Version".

NOTE: The assumption in giving the PIADS in this instance is that the client was using the device prior to the time of death, and since the last PIADS assessment (where applicable). Do not give the PIADS if the client did not use the device since the last PIADS assessment

Explain that in this particular instance, you understand that the client has passed away and you are asking the caregiver to complete the PIADS on behalf of the client.

Explain that you are asking the caregiver to use the scale to indicate how he/she thinks the device affected the client's life in the time just before he/she passed away. Explain that this information will help the researchers discover ways to improve devices for people with conditions similar to that of the loved one.

Instructions to Client/Caregiver on Completing the PIADS Before an Assistive Device is Prescribed

1. Use the standard approach to explaining what the PIADS is and how it is to be completed (see manual).
2. Explain that in this particular instance, the client has not yet received an assistive device, Therefore, what you are asking him/her to do is use the scale to indicate how he/she thinks the device will affect his/her quality of life. Explain that you are collecting this kind of information because you think it might help the research team get a better understanding of what people's concerns and issues are when they are being assessed for assistive technology.
3. In all other respects, the client/caregiver should complete the scale in the usual fashion (e.g., all items must be answered, even if some might seem odd or irrelevant to the client's circumstances).

Script for Completing the PIADS by Telephone

For the next few minutes, I would like to ask you some questions about assistive devices you might be using to help you to do your daily tasks.

(*Provide the following definition when the patient doesn't understand what an assistive device is.*)

Definition of an Assistive Device: An assistive device is any kind of device or tool that helps you achieve normal or near-normal functioning, such as a walker or wheelchair if you have difficulty walking, or a hearing aid if you have trouble hearing.

Today, I will ask you to tell me your feelings or attitudes about your _____ <insert device type here>.

I am going to read out a list of words and phrases.

For each word or phrase, I want you to tell me if your _____ <insert device type here> has made any difference in your life.

If you tell me that your _____ <insert device type here> has made a difference, I will then ask you to tell me if it has made things better or worse for you.

You may rank your response on a scale ranging from -3 to +3, with -3 being a lot worse, and +3 being a lot better.

There are no right or wrong answers. Please be as honest as you can when replying.

Do you understand what I am asking you to do?

Do you have any questions before we begin?

Let's begin with the first word or phrase.

"Competence "

(*Refer to PADS glossary if respondent has trouble with the meaning of the word or phrase, and follow the directions in the manual for this. No item can be left unanswered. Use 0 (zero) if the respondent cannot decide if there has been an impact*.)

Has your _____ <insert device type here> made you feel more or less competent?

(*If respondent says "**no**", code as 0 (zero) and move onto next item*)

(*If respondent says "**yes, more**", then follow up by asking which of the following best describes this impact*:)

"Would you say that your _____ <insert device type here> has made this
Very Much Better for You (code as +3),
Just a Little Bit Better for You (code as +1),
or Somewhere in Between (code as +2)."

(*If respondent says "**yes, less**", then follow up by asking which of the following best describes this impact*.)

"Would you say that your _____ <insert device type here> has made this
Very Much Worse for You (code as -3),
Just a Little Bit Worse for You (code as -1),
or Somewhere in Between (code as -2)."

(*Repeat this procedure for the rest of the items on the scale*.)

We have now finished this questionnaire. Thank you very much for helping us today.

PIADS Background Form – Wheelchairs #____

1. ☐ I am still using the device
   ☐ I never used the device.
   ☐ I no longer use the device that was prescribed for me because: (mark all that apply)
   Date you stopped using the device_____(m/d/y)
   a) ☐ My condition has changed.
   b) ☐ I've switched devices.
   c) ☐ I no longer use any kind of mobility device.
   d) ☐ My wheelchair is broken & not usable.
   e) ☐ Other (specify):_____

2. When did you obtain your primary mobility device(s)? Month _____ Day _____ Year _____

3. What kind of wheelchair(s) or mobility device(s) do you currently have? (mark all that apply)
   a) Manual Wheelchair with:
      1) ☐ no seat cushion/ no back support
      2) ☐ seat cushion & sling back
      3) ☐ seat cushion & back support
      4) ☐ manual dynamic recline
      5) ☐ manual dynamic tilt
      6) ☐ manual dynamic tilt & recline
   b) ☐ Electric Scooter
   c) Power Wheelchair with:
      1) ☐ seat cushion & sling back
      2) ☐ seat cushion & back support
      3) ☐ power tilt
      4) ☐ tilt and recline
      5) ☐ power tilt/recline/zero shear
      6) ☐ power tilt/recline/zero shear/power legs
      7) ☐ power wheelchair with midwheel drive
   d) ☐ Other (specify):_____

4. How do you drive or mobilize your wheelchair(s) or mobility device(s)? (mark all that apply)
   a) ☐ Direct drive with two hands
   b) ☐ One handed drive
   c) ☐ Foot Propulsion
   d) ☐ Foot Treadle Switch
   e) Joystick control ☐ Right ☐ Left
   f) ☐ Modified Joystick (e.g. U-stick, T-Stick)
   g) ☐ Midline Controller (Custom Mount)
   h) ☐ RIM Controller (Head Joystick)
   i) ☐ Peach-tree Controller
   j) ☐ Sip and Puff
   k) ☐ Tongue Switch
   l) ☐ Chin Controller
   m)☐ Mouth Stick
   n) ☐ Tiller bar
   o) ☐ Single switch access
   p) ☐ Multiple switch access
   q) ☐ Someone pushes my chair
   r) ☐ Other (specify):
   _____

5. Has there been any change in the amount of time that you use your device since getting it? (mark one)
   I use it: a) ☐ as much as I always have. b) ☐ more c) ☐ less d) ☐ other :_____

6. Why do you use your device? (mark all that apply.)
   a) ☐ It's the only way that I can get around.
   b) ☐ So that I can go to school or work.
   c) ☐ It's the only way that I can be independent.
   d) ☐ It's the only way to approach someone.
   e) ☐ Because it relieves my pain.
   f) ☐ Because it increases my sitting tolerance.
   g) ☐ So that I feel less anxious.
   h) ☐ So that I feel less self-conscious.
   i) ☐ Other (please specify):_____

In the next 3 questions please circle a number between 1 and 5.

7. How important do you feel the device is to your life?
   Not Important 1 2 3 4 5 **Extremely Important**

8. How would you rate your satisfaction with your present device?
   Not Satisfied 1 2 3 4 5 **Extremely Satisfied**

9. How much difficulty did you experience adjusting to your present device?
   Extreme Difficulty 1 2 3 4 5 **No Difficulty At All**

PIADS Background Form – VOCA s #____

1. ☐ I am still using the device
☐ I never used the device.
☐ I no longer use the device that was prescribed for me because: (mark all that apply)
Date you stopped using the device_____(m/d/y)
a) ☐ My condition has changed.
b) ☐ I've switched devices.
c) ☐ I no longer use any kind of communication device.
d) ☐ My VOCA is broken & not usable.
e) ☐ Other (specify):_____

2. When did you obtain your present communication device(s)? Month _____ Day _____ Year _____

3. What kind of communication device(s) do you currently have? (mark all that apply)
a) ☐ Standard Lightwriter
b) ☐ Lightwriter with scanner
c) ☐ Message Mate
d) ☐ Franklin
e) ☐ Walker Talker
f) ☐ The Link
g) ☐ Delta Talker
h) ☐ Liberator
i) ☐ Dynavox
j) ☐ Portable Laptop with Voice Output
k) ☐ Other (specify):_____

4. How do you access your present communication device(s)? (mark all that apply)
a) ☐ Direct Selection with two hands (touch-typing)
b) ☐ Direct Selection with one hand (hunt and peck)
c) ☐ Using your left foot
d) ☐ Using your right foot
e) ☐ Touch Screen (one-hand)
f) ☐ Touch Screen (two hands)
g) ☐ Joystick (left)
h) ☐ Joystick (right)
i) ☐ Morse Code (one switch)
j) ☐ Morse Code (two switches)
k) ☐ Mouth Stick
l) ☐ Single switch Scanning
m)☐ Trackball with hand
n) ☐ Trackball with foot
o) ☐ Headmouse
p) ☐ Myoswitch
q) ☐ Cyberlink
r) ☐ Eye-blink switch
s) ☐ VisionKey
t) ☐ Sip and Puff
u) ☐ Tongue Switch
v) ☐ Other (specify):_____

5. Has there been any change in the amount of time that you use your device since getting it? (mark one)
I use it: a) ☐ as much as I always have. b) ☐ more c) ☐ less d) ☐ other :_____

6. Why do you use your device? (mark all reasons that apply)
a) ☐ It's the only way I can speak to someone.
b) ☐ So people can better understand my speaking.
c) ☐ So that I feel less anxious when I speak.
d) ☐ So that I feel less self-conscious.
e) ☐ So people feel more comfortable with me.
f) ☐ Other (please specify): _____

In the next 3 questions please circle a number between 1 and 5.

7. How important do you feel the device is to your life?
Not Important 1 2 3 4 5 **Extremely Important**

8. How would you rate your satisfaction with your present device?
Not Satisfied 1 2 3 4 5 **Extremely Satisfied**

9. How much difficulty did you experience adjusting to your present device?
Extreme Difficulty 1 2 3 4 5 **No Difficulty At All**

PIADS Background Form - Writing Aids #____

1. ☐ I am still using the device
   ☐ I never used the device.
   ☐ I no longer use the device that was prescribed for me because: (mark all that apply)
   Date you stopped using the device_____(m/d/y)
   a) ☐ My condition has changed.
   b) ☐ I have switched writing aids.
   c) ☐ I no longer use any writing aid.
   d) ☐ My writing aid is broken & not usable.
   e) ☐ Other (specify):_____

2. When did you obtain your present writing aid device? Month _____ Day _____ Year _____

3. What kind of writing aid(s) do you currently have? (mark all that apply)
   a) ☐ Laptop
   b) ☐ Desktop System
   c) ☐ Other (specify):_____

4. How do you access your writing aid? (mark all that apply)
   a) ☐ Direct Selection with two hands (touch-typing)
   b) ☐ Direct Selection with one hand (hunt and peck)
   c) ☐ Touch Screen
   d) Using your foot ☐ left ☐ right
   e) Joystick using your hand ☐ left ☐ right
   f) Morse Code using ☐ 1 switch ☐ 2 switches
   g) ☐ Mouth Stick
   h) ☐ Mouse with on-screen keyboard
   i) ☐ Trackball with on-screen keyboard
   j) ☐ Head Mouse with on screen keyboard
   k) ☐ Single Switch Scan
   l) ☐ Myoswitch
   m) ☐ Eye-blink switch
   n) ☐ Cyberlink
   o) ☐ VisionKey
   p) ☐ Voice Recognition
   q) ☐ Sip and Puff
   r) ☐ Tongue Switch
   s) ☐ Other (specify):
   _____

5. Has there been any change in the amount of time that you use your device since getting it? (mark one)
   I use it: a) ☐ as much as I always have. b) ☐ more c) ☐ less d) ☐ other :_____

6. Why do you use your device? (mark all that apply.)
   a) ☐ To write to someone.
   b) ☐ To complete my correspondence.
   c) ☐ It's the only way I can work.
   d) ☐ To speak to someone.
   e) ☐ So people can understand me.
   f) ☐ To feel less anxious.
   g) ☐ So that I feel less self-conscious.
   h) ☐ People feel more comfortable with me when I use it.
   i) ☐ Other (please specify):_____

In the next 3 questions please circle a number between 1 and 5.

7. How important do you feel the device is to your life?
   Not Important 1 2 3 4 5 **Extremely Important**

8. How would you rate your satisfaction with your present device?
   Not Satisfied 1 2 3 4 5 **Extremely Satisfied**

9. How much difficulty did you experience adjusting to your present device?
   Extreme Difficulty 1 2 3 4 5 **No Difficulty At All**

PIADS Background Form – E.C.U. s #__

1. ☐ I am still using the device.
   ☐ I never used the device.
   ☐ I no longer use the device that was prescribed for me because: (mark all that apply)
   Date you stopped using the device_____(m/d/y)
   a) ☐ My condition has changed.
   b) ☐ I have switched E.C.U.'s.
   c) ☐ I no longer use any E.C.U.
   d) ☐ My ECU is broken & not usable.
   e) ☐ Other (specify):_____

2. When did you obtain your present E.C.U. device(s)? Month _____ Day _____ Year _____

3. What kind of E.C.U.(s) do you currently have? (mark all that apply)
   a) ☐ Scanner to operate: TV, VCR, CD
   b) ☐ Bed Controller
   c) ☐ Scanning Telephone
   d) ☐ Door Operators
   e) ☐ Window blinds
   f) ☐ Satellite Dish
   g) ☐ Lights
   h) ☐ Air Conditioner / heater
   i) ☐ Radio
   j) ☐ Cell Phone
   k) ☐ Water Dispenser
   l) ☐ Specialized Computer Controls
   m) ☐ Other (specify):_____

4. How do you access your E.C.U.? (mark all that apply)
   a) With hand(s) ☐ right ☐ left
   b) With your foot/feet ☐ right ☐ left
   c) Joystick control ☐ right ☐ left
   d) ☐ Modified Joystick (e.g. U-stick, T-Stick)
   e) ☐ Midline Controller (Custom Mount)
   f) ☐ RIM Controller (Head Joystick)
   g) ☐ Peach-tree
   h) ☐ Sip and Puff
   i) ☐ Mouth Stick
   j) ☐ Tongue Switch
   k) ☐ Tiller bar
   l) ☐ Voice Recognition Control
   m) ☐ Other (specify):
   _____

5. Has there been any change in the amount of time that you use your device since getting it? (mark one)
   I use it: a) ☐ as much as I always have. b) ☐ more c) ☐ less d) ☐ other :_____

6. Why do you use your device? (mark all that apply)
   a) ☐ It's the only way I can operate things independently.
   b) ☐ So that I feel less anxious.
   c) ☐ So that I feel less self-conscious.
   d) ☐ So that I can manage my environment.
   e) ☐ Other (please specify):
   _____

In the next 3 questions please circle a number between 1 and 5.

7. How important do you feel the device is to your life?
   Not Important 1 2 3 4 5 **Extremely Important**

8. How would you rate your satisfaction with your present device?
   Not Satisfied 1 2 3 4 5 **Extremely Satisfied**

9. How much difficulty did you experience adjusting to your present device?
   Extreme Difficulty 1 2 3 4 5 **No Difficulty At All**

PIADS Background Form -Mechanical Ventilation #____

Client Name:_____ Today's Date:_____
(first name then last name) month/day/year

Client Diagnosis:_____ Client Date of Birth:_____
month/day/year

Client Gender:_____ Client List ID (Office use)_____

The following information is helpful to us in understanding your responses to the other questionnaires. Please mark (✓) the responses that best describe your situation.

Important
If you are filling out this form on behalf of client or assistive device user please interpret questions referring to "you" and "T" as if this were the user. For instance if the question asks "how important do **you** feel the device is to **your** life", read this as "how important **does the user** feel the device is to **his/her** life".

Part A. The following questions are about the completion of this form.

1. Who is filling out this form? (mark one)
   a) ☐ Client
   b) ☐ Caregiver
   c) ☐ Researcher
   d) ☐ Healthcare Professional
   e) ☐ Other:_____

2. Who is providing the responses to this form? (mark one)
   a) ☐ Client
   b) ☐ Caregiver

3. How is this form being filled out? (mark one)
   a) ☐ Face to face
   b) ☐ E-mail
   c) ☐ Telephone
   d) ☐ Regular mail
   e) ☐ Other:_____

4. What is the profession of the individual who prescribed this device? (mark one)
   a) ☐ Medical Doctor
   b) ☐ Respiratory Therapist
   c) ☐ Other:_____

Part B. The following questions are about your general health.

1. Do you have any other assistive devices? (Mark all that apply)
   a) ☐ Hearing Aids (Please Specify Type)_____
   b) ☐ Vision Aids (Please Specify Type)_____
   c) ☐ ADL Aids (e.g. toilet seat, grab bars etc.) (Please Specify)_____
   d) ☐ Mobility Aids (Please Specify)_____
   e) ☐ Communication Device/Computer (Please Specify)_____
   f) ☐ Environmental Controls (Please Specify)_____

2. Have you been experiencing difficulty sleeping? ☐ Yes ☐ No

   If so, for how long? _____

3. Are you snoring at night (Sleep Apnea)? ☐ Yes ☐ No

4. Do you require suctioning? ☐ Yes ☐ No

   If so, how often? _____

5. Do you experience any of the following? (Mark all that apply)

☐ stomach aches	☐ ear pain	☐ other (specify):
☐ heartburn	☐ sinus pain	_____
☐ headaches	☐ eye pain	☐ no aches or pains

6. Can you breathe at all without Mechanical Ventilation? ☐ Yes ☐ No

   If so, for how long? _____

Part C. The following questions are about your breathing device.

1. I no longer use the breathing device because: (mark all that apply)
   a) ☐ My medical or physical condition has changed.
   b) ☐ I have switched to a different kind of breathing device.
   c) ☐ Date you changed device_____(month/day/year)
   d) ☐ Other (please comment):_____
   (If have stopped using a breathing device then you have completed the form.)

Otherwise Please Continue

2. ☐ I am still using the breathing device that was prescribed for me the last time I got a prescription.

3. What kind of breathing device(s) do you currently have? (mark all that apply)
   a) ☐ Bipap
   b) ☐ Nighttime ventilation (with tracheostomy)
   c) ☐ Full 24 hour ventilator
   d) ☐ Other (please specify): _____

4. When did you obtain your present breathing device(s)?
   Month _____ Day _____ Year _____

5. Was the initial decision to use Mechanical Ventilation made by you?
   ☐ **Yes, If yes then go to Question 6, on next page.**
   ☐ **No, If no then go to Question 8, on next page.**

Please Continue

6. How difficult was it for you to make the decision to use a breathing device? (mark between 1 and 5)

Not Difficult				**Extremely Difficult**
1	2	3	4	5

7. What factors influenced you to make the decision to choose the breathing device?

_____

_____

8. How difficult was it for you to make the decision to continue to use a breathing device? (mark between 1 and 5)

Not Difficult				**Extremely Difficult**
1	2	3	4	5

9. What factors influenced you to make the decision to continue to use the breathing device?

_____

_____

10.a. Has there been any change in the amount of time that you use your device since getting it?

i) ☐ No. I use it as much as I always have.
ii) ☐ Yes. I use it more than I did when I first got it.
iii) ☐ Yes. I use it less than I did when I first got it.
iv) ☐ Other (please specify):_____

10.b. If there has been a change, what is the reason for the change?

_____

_____

11. How would you rate your satisfaction with your present device? *(mark a number between 1 and 5)*

Not Satisfied				**Extremely Satisfied**
1	2	3	4	5

12. How much difficulty did you experience adjusting to your present device? *(mark a number between 1 and 5)*

Extreme Difficulty				**No Difficulty At All**
1	2	3	4	5

13. If you have any additional comments, please writing them in the space below.

_____

_____

_____

When you have completed this questionnaire, please return it to:
Pearl Gryfe, OT(C),
Assistive Technology Clinic
Sunnybrook Health Science Centre.

Please call Pearl at (416) 480-6883 if you have any comments or concerns about this questionnaire.

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Version 4.4

QUALITY OF LIFE-5

The QOL-5 questionnaire is a self-administered questionnaire with items rated on a Likert scale. The questionnaire consists of 5 items based on an "integrative" theory of the quality of life, meaning that it organizes a number of theories on the quality of life into a spectrum that spans the extremes of subjective and objective quality of life.

Abbreviated Name: QOL-5
Author(s): J. S. Lindholt , Søren Ventegodt
Purpose: Describing the quality of life of a population or patient group
Population: Adult
Age Range : 18 and over
Type of Instrument: Quality of Life
Mode of Administration:

Rater:	Self-administered
Time required:	1-5 minutes
Response Options:	Likert scale
Scoring:	Global score
	Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 5
Original Language: English

Copyright: Søren Ventegodt& J. S. Lindholt

Contact for information and permission to use:

Søren Ventegodt MD, MMedSci
Quality-of-Life Research Center,
Nordic School of Holistic Medicine &
Research Clinic for Holistic Medicine
/Forskningscenter for Livskvalitet
Teglgårdsstræde 4-8
1452K København/Copenhagen
Phone + 45 33 14 11 13
FAX: + 45 33 14 11 23
E-mail: ventegodt@livskvalitet.org
Web: http://www.livskvalitet.org

J. S. Lindholt, M.D., Ph.D.
Frederik Vs Vej 15
3rd Floor, Room 21
DK-2100 Copenhagen
Denmark
Email: jslindholt@mail.tele.dk

Dimensions covered by the questionnaire :

- Subjective QoL
- Objective QoL
- Existential QoL

Key References:

1. Lindholt1 JS, Ventegodt S, Henneberg EW. Development and Validation of QoL5 for Clinical Databases. A Short, Global and Generic Questionnaire Based on an Integrated Theory of the Quality of Life

Objective: To develop and validate a short, global, and generic quality of life (QoL) questionnaire for clinical databases. The construct validity and item weighting of existing questionnaires are increasingly questioned. Design: Cross-sectional population study. Subject: 2460 Danes aged 18–88 years, randomly selected through the Danish Central Person Registry. Interventions: Ten questions covering the spectrum of the integrative theory of QoL together with the Nottingham Health Profile (NHP), Sickness Impact Pro□ le (SIP), and self-estimated QoL questionnaire were sent by mail. A test-retest study of 50 people was conducted after one month. Main outcome measures: Construct and criterion validity, reliability, and sensitivity. Results: QoL5 correlations with SIP, NHP, Self-estimated QoL were 0.37, 0.52, and 0.76, respectively, and increased among those who were unwell. Cronbach's a was 0.69. All correlations in Siegel's test were over 0.6, and the test-retest correlation was 0.82. Only 12 respondents in each group will be needed to detect a difference of 10% in the QoL score between two groups. Conclusions: QoL5 is a valid global and generic QoL measurement. Despite the use of only □ ve questions, internal consistency and sensitivity were acceptable. So a relevant and practical outcome measurement is available for clinical databases.

2. Ventegodt S, Hilden J, Merrick J. Measurement of Quality of Life I. A Methodological Framework The Scientific World Journal 2003; 3: 950-961

Despite the widespread acceptance of quality of life (QOL) as the ideal guideline in healthcare and clinical research, serious conceptual and methodological problems continue to plague this area. In an attempt to remedy this situation, we propose seven criteria that a quality-of-life concept must meet to provide a sound basis for investigation by questionnaire. The seven criteria or desiderata are: (1) an explicit definition of quality of life; (2) a coherent philosophy of human life from which the definition is derived; (3) a theory that operationalizes the philosophy by specifying unambiguous, nonoverlapping, and jointly exhaustive questionnaire items; (4) response alternatives that permit a fraction-scale interpretation; (5) technical checks of reproducibility; (6) meaningfulness to investigators, respondents, and users; and (7) an overall aesthetic appeal of the questionnaire. These criteria have guided the design of a validated 5-item generic, global quality-of-life questionnaire (QOL5), and a validated 317-item generic, global quality-of-life questionnaire (SEQOL), administered to a well-documented birth cohort of 7,400 Danes born in 1959–1961, as well as to a reference sample of 2,500 Danes. Presented in outline, the underlying integrative quality-of-life (IQOL) theory is a meta-theory. To illustrate the seven criteria at work, we show the extent to which they are satisfied by one of the eight component theories. Next, two sample results of our investigation are presented: satisfaction with one's sex life has the expected covariation with one's quality of life, and so does mother's smoking during pregnancy, albeit to a much smaller extent. It is concluded that the methodological framework presented has proved helpful in designing a questionnaire that is capable of yielding acceptably valid and reliable measurements of global and generic quality of life.

3. Ventegodt S, Kandel I, Merrick J. Principles of Holistic Medicine: Global Quality of Life Theory, Research and Methodology. Hippocrates Scientific Publications New Hyde Park, New York. 2005.

4. Ventegodt S, Kandel I, Merrick J. Principles of Holistic Medicine: Quality of Life and Health. Hippocrates Scientific Publications New Hyde Park, New York. 2005.

Dear Mr/Mrs/Miss

To evaluate the benefits of appointments and treatments in the health services, we would like you to answer a few questions about your quality of life.

Please consider the questions carefully before answering. Then draw a circle around the most suitable answer.

Q1. How do you consider your **physical health** at the moment ?

1 Very good
2 Good
3 Neither good or bad
4 Bad
5 Very bad

Q2. How do you consider your **mental health** at the moment?

1 Very good
2 Good
3 Neither good or bad
4 Bad
5 Very bad

Q3. How is your relationship with your **partner** at the moment ?

1 Very good
2 Good
3 Neither good or bad
4 Bad
5 Very bad /I do not have one

Q4. How are your relationships with your **friends** at the moment ?

1 Very good
2 Good
3 Neither good or bad
4 Bad
5 Very bad

Q5. How do you **feel about yourself** at the moment ?

1 Very good
2 Good
3 Neither good or bad
4 Bad
5 Very bad

Please make certain that you have answered **all** the questions. Thank you for your help.

"QoL5". Copyright 2001. The Quality-of-Life Research Centre, Teglgaardsstræde 4-8, DK-1452 Copenhagen.
Phone +45 33 14 11 13 Fax: +45 33 14 11 23
This questionnaire is hereby released for non-commercial, scientific use. Please apply for written permission for all commercial or non-scientific use to The Quality-of-Life Research Center.

Objective QoL (from QI and QII on health) = (I ‡ II)/2. Existential QoL (from QIII and QIV on relationships) = (III ‡ IV)/2. Subjective QoL (from QV on wellbeing) = V. Overall QoL = (Objective QoL ‡ Existential QoL ‡ Subjective QoL)/3 = ((I ‡ II)/ 2) ‡ ((III ‡ IV)/2) ‡ V)/3.

Roman numerals refer to the scored, encircled answer of the question with the same number, i.e.: if the respondent answers “2” in Q. 1, then I = (110 – (answer £ 20))% = (110 ¡ 2 £ 20)% = 70%. Example: If the □ ve answers obtained from Q.s 1–5 are 1, 2, 3, 4 and 5, respectively, the Overall QL = ((90% ‡ 70%)/ 2 ‡ (50% ‡ 30%)/2 ‡ 10%)/ 3 = 43.3%

QUALITY OF DYING AND DEATH

The Quality of Dying and Death Instrument contains 31 items asking the respondent to report on and rate the quality of the dying experience in the decedent's last 7 days if the patient was unconscious or unresponsive throughout the last 7 days, then the last month's experience before death. Items are rated on a scale of 0 (terrible experience) to 10 (almost perfect experience). A total score is calculated by adding the scores on all items and dividing this score by the number of items answered. This mean score is multiplied by 10 to construct a scale ranging from 0 to 100, with higher scores indicating a better quality of dying and death.

Abbreviated Name: QODD
Author(s): J. Randall Curtis, Donald L. Patrick
Purpose: For assessing the quality of dying and death
Population: Terminal patients
Age Range : 18 and over
Type of Instrument: Quality of Life
Mode of Administration: Interviewer administered

Rater:	Interviewer-administered
Time required:	15-20 minutes
Response Options:	Yes/no - 0- to 10-point Likert scale
Scoring:	Global score Scores by items
Score Direction:	Higher scores show better QoL

Number of Items: 31
Original Language: English

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Contact for information and permission to use:

J. Randall Curtis, MD, MPH
Professor of Medicine
Pulmonary and Critical Care Medicine
University of Washington
Box 359762 325 Ninth Avenue
Seattle, WA 98104 USA
Phone: +1 (206) 731-3356
Fax: +1 (206) 731-8584
E-mail: jrc@u.washington.edu

Dimensions covered by the questionnaire :

- Symptoms
- Patient preference
- Satisfaction with care

Key References:

1. Patrick DL, Engelberg RA, Curtis JR. Evaluating the quality of dying and death. J Pain Symptom Manage 2001; 22:717-26

We propose a model for evaluating the quality of dying and death based on concepts elicited from literature review, qualitative interviews with persons with and without chronic and terminal conditions, and consideration of desirable measurement properties. We define quality of dying and death as the degree to which a person's preferences for dying and the moment of death agree with observations of how the person actually died, as reported by others. Expected level of agreement is modified by circumstances surrounding death that may prevent following patient's prior preferences. Qualitative data analysis yielded six conceptual domains: symptoms and personal care, preparation for death, moment of death, family, treatment preferences, and whole person concerns. These domains encompass 31 aspects that can be rated by patients and others as to their importance prior to death and assessed by significant others or clinicians after death to assess the quality of the dying experience. The proposed model uses personal preferences about the dying experience to inform evaluation of this experience by others after death. This operational definition will guide validation of after-death reports of the quality of dying experience and evaluation of interventions to improve quality of end-of-life care.

2. Curtis JR, Wenrich MD, Carline JD, Shannon SE, Ambrozy DM, Ramsey PG. Understanding physicians' skills at providing end-of-life care perspectives of patients, families, and health care workers. J Gen Intern Med. 2001 Jan;16(1):41-9

3. Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. J Pain Symptom Manage. 2002 Jul;24(1):17-31

A reliable and valid measure of the quality of the dying experience would help clinicians and researchers improve care for dying patients. To describe the validity of an instrument assessing the quality of dying and death using the perspective of family members after death and to identify clinical correlates of a high quality death, a retrospective cohort study evaluated the 31-item Quality of Dying and Death (QODD) questionnaire. The questionnaire was administered to family members of patients who died in Missoula county Montana in 1996 and 1997. The interview included questions assessing symptoms, patient preferences, and satisfaction with care. Measurement validity was examined for item and total scores and reliability analyses for the QODD total score were assessed. Construct validity was assessed using measures of concepts hypothesized to be associated with the quality of dying and death. There were 935 deaths, of which 252 (27.0%) family interviews were represented. Non-enrolled decedents were not significantly different from enrolled decedents on age, sex, cause of death, or location of death. We excluded sudden deaths (n = 45) and decedents under age 18 (n = 2), leaving 205 after-death interviews. A total QODD score, on a scale from 0 to 100 with higher scores indicating better quality, ranged from 26.0 to 99.6, with a mean of 67.4 and Cronbach's alpha of 0.89. The total QODD score was not associated with patient age, sex, education, marital status, or income. As hypothesized, higher QODD scores were significantly associated with death at home ($P < 0.01$), death in the location the patient desired ($P < 0.01$), lower symptom burden ($P < 0.001$), and better ratings of symptom treatment ($P< 0.01$). Although the total score was not associated with the presence of an advance directive, higher scores were associated with communication about treatment preferences ($P < 0.01$), compliance with treatment preferences ($P < 0.001$), and family

satisfaction regarding communication with the health care team ($P < 0.01$). Availability of a health care team member at night or on weekends was also associated with a higher QODD score ($P < 0.001$). The QODD total score demonstrated good cross-sectional validity. Clinicians caring for dying patients should focus on improving communication with the patient and family and improving symptom assessment and treatment. Health care teams should focus on continuity of care, including having a team member familiar with the patient available for calls at nights and on weekends. Future work will assess the potential role of the QODD in improving the quality of the dying experience.

QODD: INSTRUCTIONS FOR INTERVIEWERS

University of Washington School of Medicine

1. Text to be read to respondent

a. All information that is to be read to respondents (instructions, questions, response options) is in lower case, **bolded** font.

b. Response options that should be read to patients are preceded with an ellipsis:"….". Read all the response options before pausing for an answer. In the example below, the interviewer would read "less than 1 hour, 1 to 4 hours, 4 to 8 hours, or 8 or more hours" before pausing for a response.

Example: On the days that you saw your loved one, what was the most time you spend with him/her?….

Less than 1 hour	1-4 hours	4-8 hours	8 or more hours
1	2	3	4

c. Response options that do not need to be read to respondents are in UPPER case, non-bolded font. In these cases, the respondent will provide the answer without being read the response options. YES/NO responses are generally of this type.

Example: At any time during the last seven days of Mrs. Johnson's life, did she/he talk with you in a way that you could understand her?

1	YES
2	NO

d. Numbers associated with response options should not be read to respondents; they are for coding purposes.

e. Blanks beginning with "X_____" are to be filled in with the patient's name.

Example: "The next set of questions asks about the quality of X_____'s experience of dying and death" should be read as "The next set of questions asks about Mr. Jones's experience of dying and death".

f. Choose the appropriate pronoun from phrases like "he/she" or "him/her".

Example: "In the last seven days of his/her life, how often did x_____ listen to music?" should be read as "In the last seven days of her life, how often did Mrs. Johnson listen to music?"

2. Directions to the interviewer

a. Directions to the interviewer are enclosed in parentheses and are in UPPER case, *italicized*, non-bolded font. This includes directions about using response cards, marking answers and following skip patterns.

Example: "First, I will be asking you how often Mr. Jones experienced each item using a scale where 0 is "none of the time" and 5 is "all of the time". (SHOW CARD #1)

3. Special instructions:

a. Prompts: The QODD items are made up of two parts. In Section A, the first part asks, "How often?" and the second part asks "How would you rate this aspect?" In Sections B,C, and D, the first part asks "Did _____ happen?" and the second part asks, "How would you rate this aspect?".

It may be necessary to add some prompts to help respondents with the second part of the question. In these prompts, the interviewer repeats the body of the question. For example, for the question about spending time with other family and friends, it may be necessary to ask the second part as "How would you rate this aspect of the dying experience, that is, spending time with family and friends". This kind of prompt is appropriate whenever the interviewer feels that the respondent is having difficulty remembering the referent for the item or is straying from the topic.

Another prompt which may be needed throughout the QODD redirects the respondent's attention to the response card. This is needed at times when the respondent has information to share about the question but is not providing a rated or scaled response. Some helpful statements are:

"Overall, what would that be on this scale here?"
" Using this card, how would you rate that?"
"Which number best fits?"

b. Verbal Cue Cards: Some respondents may have difficulty with the rating response scale used in part B of each item. If respondents are having difficulty picking values or deciding on the meaning of the values, it might be useful to try the "Verbal Cue Card #2" which assigns a verbal label to each value on the 10 point scale. This should be used only after the unlabeled version (Card #2) has been tried unsuccessfully.

c. Skip patterns: In Section A, if respondents answer "don't know" or refuse to answer part A of a question, then the interviewer should skip part B and go on to the next question. Part B should be coded "888". We are assuming that if the respondent doesn't know if a particular experience occurred or does not want to answer part A, then it is unlikely that he/she will be able or willing to rate how it went. Note: items that are skipped as directed in the questionnaire are always coded "888".

QODD: SIGNIFICANT OTHER AFTER-DEATH INTERVIEW CODING MANUAL NON-UNIVERSITY OF WASHINGTON SITES

General Coding Conventions, Rules

1. The following three-digit numbers are used for missing values:

   666 = 'not asked' either by the interviewer or not included in the questionnaire
   777 = 'refused'
   888= 'skipped, not applicable'
   999 = 'don't know'

   NOTE: 888 is always used when a question is skipped as directed in the questionnaire. For example, part B will be coded "888" if the respondent answers "don't know" or refuses to answer part A of a question.

2. Dates:
   Years are entered as 4 digit numbers
   Months, days are entered as 2 digit numbers

3. Seven day vs. last month versions
   7 = seven day recall
   30 = 30 day recall
   The same variable names are used, regardless of which version has been administered. Versions are identified by the variable, **VERSION**

PART I, "CIRCUMSTANCES"

Page 1 - Cover Page

Patient ID (PID)
No missing values

Significant other ID (SID)
No missing values

Interview date (INTMO, INTDY, INTYR)
Month, day are 2 digit numbers.
Year is a 4 digit number (ex: 2000).
No missing values.

Start and stop time (STRTIME, STPTIME)
Time, with AM or PM.

For patients interviewed over a number of sessions, field is left blank.

Time (MINUTE)
Minutes required to complete the questionnaire.
If multiple sessions were used, calculate the total time.

Version (VERSION)
7 day recall = 7
30 day recall = 30

Pages 2-4 Circumstances of Death

Question 1-7

Q.1 Date of death (DTHM, DTHMDY, DTHYR)
Month, day are 2 digit numbers.
Year is a 4 digit number (ex. 1999).
No missing values.

Is date correct (DTHDTOK)?
1 = yes, 2 = no

Corrected date (ADTHM, ADTHDY, ADTHYR)
If date is incorrect, enter corrected date from significant other.
If date is correct, enter 888/888/888.

Q. 2. Days seeing patient over past week? (DAY1, DAY2, DAY3, DAY4, DAY5, DAY6, DAY7)
0 = not seen, 1 = seen.

Q. 3 Where was patient on each of these days? (PLDAY1, PLDAY2,PLDAY3, PLDAY4, PLDAY5, PLDAY6, PLDAY7)
1 = patient's own home
2 = significant other's home
3 = other's home
4 = hospital
5 = in-patient hospice
6 = nursing home
7 = other

Q. 4 What was most time spent with patient? (MSTIME).
1 = < 1hour
2 = 1-4 hours
3 = 4-8 hours
4 = >=8 hours

Q. 5 Least number of hours spent with patient? (LSTIME).
1 = < 1hour
2 = 1-4 hours
3 = 4-8 hours
4 = >=8 hours

Q. 6 During the last year, how frequently see patient? (FRQYR).
1 = daily
2 = at least once a week
3 = at least once a month
4 = less than once a month

Q. 7 How long before death was patient aware they were dying? (AWARE)
1 = never aware
2 = one week before death
3 = 2-4 weeks before death
4 = 2-6 months before death
5 = 6-12 months before death

Screening Question (SEVDAY)
Did patient talk with you in a way you could understand during the last seven days of life?
1 = yes-→ use 7 day version, 2 = no-→ use 30 day version

PART 2, "QODD"

Page 5-Cover Page

No data entry required for this page; this cover page allows a link between Part 1 and Part 2 with Part 2 selected from either the 7-day or 30-day version.

Pages 6-12 Quality of Dying and Death, Section A (QODD)

Question QODD Example, 1-16

Example: Frequency of listening to music (QODEXA)
Values 0-5.
Quality of experience, if listened to music (QODEXB)
Values 0-10.

Q. 1a-16b (QOD1a - QOD16b)
Frequency items (QOD__a)
0 = none of the time
1 = a little bit of the time
2 = some of the time
3 = a good bit of the time
4 = most of the time
5 =all of the time

Rating of quality of experience (QOD_b)
Values 0-10
0 = terrible experience
10 = almost perfect experience
888 if Part 'a' = 999 (don't know) or 777 (no response, refuse).

The following questions require 888 if "not applicable"
Q. 12 Spending time with spouse, partner? (QOD12a,b)
Q. 13 Spending time with children (QOD13a,b)
Q. 16 Spending time with pets (QOD16a,b)

Pages 13-17 Quality of Dying and Death, Sections B,C (QODD)

Questions 17a - 28b

NOTE: VARIABLE NAMES DO NOT ALWAYS MATCH QUESTION NUMBERS.

Q. 17a, 18a, 19a, 20a, 21a, 22a, 23a, 24a, 25a, 26a, 27b, 28a
(QOD17A, QOD18A, QOD21B, QOD19A, QOD22A, QOD23A, QOD24A, QOD25A, QOD26A, QOD27B, QOD28A, QOD20A)
1= yes, 2 = no

Q. 17b, 18b, 19b, 20b, 21b, 22b, 23b, 24b, 25b, 26b, 27b, 28b
(QOD17B, QOD18B, QOD21C, QOD19B, QOD22B, QOD23B, QOD24B, QOD25B, QOD26B, QOD27C, QOD28B, QOD20B)

Values 0-10
888 if Part 'a' = 999 (don't know).

Pages 17-19 Quality of Dying and Death, Sections D,E (QODD)

Q. 29a Place of death

Home (PADIE3)	
Surrogate's home (PADIE6)	
Other home (PADIE7)	text (HOMETX)
Hospital (PADIE12)	text (HOSPIT)
In-patient hospice (PADIE5)	text (HOSPTX)
Nursing home (PADIE4)	text (NURSTX)
Other (PADIE9)	text (OTHDIE)
Don't know	

0 = not endorsed, 1 = endorsed.
If respondent answers 'don't know', 999 for all response options.
If respondent provides no response, 777 for all response options.

Q. 29b Rating of place of death (PADIEB)
Values 0-10.
888 if respondent didn't know where patient died.

Q. 30a Anyone present at moment of death? (PRESA)
1 = yes, 2 = no, 999 = don't know, 777 = no response, refuse.

Q. 30 b Rating of this aspect of death (PRESB)
Values 0-10
888 if PRESA = 999 or 777.

Q. 31a State at time of death (QOD33A)
1 = awake, 2 = asleep, 3 = in a coma/ unconscious,
999 = don't know, 777= refused, no response

NOTE: The variable label does not match the question number.

Q. 31b Importance of preferred state of death (QOD33B)
Values 0-10
888 if QOD33A = 999 or 777.

Q. 32 Rating of quality of life during last 7/30 days of patient's life?(QODQOLA)
Values 0-10

Q. 33 Rating of quality of the moment of patient's death? (QODQOLB)
Values 0-10

Did interviewer use verbal cue card for the QODD? (QODCUE)
1 = yes, 2 = no.

Page 20-21 Demographics

Questions 1-5

Q. 1 Significant other's relationship to patient (REL)
1 = spouse
2 = child
3 = sibling
4 = friend
5 = parent
6 = other relative
7 = other text to describe other (RELTXT)
Enter text if '7' endorsed.

Q. 2 Respondent's birthdate (BRTHMO, BRTHDY, BRTHYR)
Birth month (1-2 digits)
Birth day (1-2 digits)
Birth year (4 digits)

Q. 3 Length of time to travel to patient's home? (CLOSEHR, CLOSEMN)
Hours to travel (1-2 digits), minutes to travel (1-2 digits, up to 60).
If significant other and patient live in same home:
CLOSEHR=0, CLOSEMN = 0
If only hours are completed, enter 0 for minutes.
If only minutes are completed, enter 0 for hours.

Q. 4 Length of time known patient? (KNOWYR, KNOWMO)
Number of years (1-2 digits)
Number of months (1-2 digits, up to 12)
If only years are provided, enter 0 for months.
If not known, KNOWYR = 999, KNOWMO = 999.

Q. 5 Respondent's gender (SEX)
1= female, 2 = male.

Page 21, Demographics

Questions 6-7

Q. 6 Respondent's race, ethnicity (WHITE, AFAM, HISP, ASIAN, NATAM, RACEOTH, RACETX)
1 = yes, 2 = no.
Enter value for all race, ethnicity variables.
If RACEOTH = 1, enter text into RACETX.

Q. 7 Respondent's education (ED)
1= no formal school
2 = k-8
3 = some high school
4 = high school diploma or GED
5 = some college
6 = 4 year college degree,
7 = graduate or professional school.

Page 22, Interviewee Assessment

Questions 1-4

Q. 1 Would you like to continue? (CONT)
1 = yes, 2 = no

Q 2. Burden? (BURDEN).
Values 0-10.
If CONT = 2 (no), BURDEN = 888.

Q. 3 Anything about quality of dying we should have asked but didn't? (COMMENT)
Text field
Enter NO if no comments
Use 666 if not asked

Q. 4 Anything that would have made questionnaire easier? (EASY)
Text field
Enter NO if no comments
Use 666 if not asked

Page 23, Interviewer Assessment

Questions 1-5

Q. 1 Completeness of interview (INT1)
1 = yes, 2 = no.

Q. 2 Reasons for incomplete interview (INT2A-INT2F)
If interview complete, enter 888.
If interview incomplete, enter 1= yes, 2 = no.

Q. 3 Quality of Data (INT3, INT3TXT)
1 = poor, 2=fair, 3 = good.
If data quality =good, leave INT3TXT blank.
If data quality =fair, poor, enter text into INT3TXT.

Q. 4 Method of interview (INT4)
1= in person, 2 = by phone.

Q. 5 Interviewer name (INTFN, INTLN)
First name and last name of interviewer.

QODD: SIGNIFICANT OTHER AFTER DEATH INTERVIEW

Part I: Circumstances
Part II: Seven day version
Last month version
Demographics
Interviewee assessment
Interviewer assessment

UNIVERSITY OF WASHINGTON SCHOOL OF MEDICINE

QODD: SIGNIFICANT OTHER
AFTER DEATH INTERVIEW

*** CIRCUMSTANCES – PART 1 ***

QUESTIONNAIRE FOR ADMINISTRATION

For Non-University of Washington Sites

PATIENT ID: ____ ____ _____

SIGNIFICANT OTHER ID: ____ ____ ____

INTERVIEW DATE ____ ____ / ____ ____ / ____ ____ ____ ____
MONTH DAY YEAR

START TIME ____ ____ : ____ ____

STOP TIME ____ ____ : ____ ____

TOTAL MINUTES: ____ ____ _____

VERSION: **7 day recall** **7**
30 day recall **30**

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INTRODUCTION

During this interview, I will ask you a variety of questions about the last days of your loved one's life. I realize that this may be a difficult topic to discuss given all that has happened for you recently. So, if you feel uncomfortable answering a question or need to stop the interview and reschedule for another time, please let me know. Everything you say is kept confidential. If you do not understand a question, stop me and I will try to explain it to you.

CIRCUMSTANCES OF DEATH

1. **According to our records, your loved one died on:** _____/_____/_____
   MONTH DAY YEAR

   Is this correct?

   1 YES

   2 NO → **What is the correct date?** _____/_____/_____
   MONTH DAY YEAR

(ON THE LINES BELOW, FILL IN THE DATES AND DAY FOR THE WEEK BEFORE THE PATIENT'S DEATH. FILL IN BEFORE THE INTERVIEW WITH THE FAR LEFT DATE THE FIRST DAY OF THE LAST WEEK OF LIFE AND THE FAR RIGHT DATE THE DATE OF DEATH.)

In this beginning section, I want to ask about the last 7 days of x_____'s life. I've looked this up in the calendar and she/he died on _____ so we want to look from _____ to _____. *(POINT TO THE DATES AS YOU READ THESE INSTRUCTIONS)*

___/___	___/___	___/___	___/___	___/___	___/___	___/___
date/day	*date/day*	*date/day*	*date/day*	*date/day*	*date/day*	*date/day*

(7^{th} day before death) *(day of death)*

2. **During the seven days before X_____'s death, on which days did you see him/her?** *(CIRCLE EACH DAY THAT RESPONDENT SAW PATIENT)*

1 2 3 4 5 6 7

3. Where was your loved one on each of these days?

(FILL IN NAME OF PLACE. USE " IF PLACE REMAINS SAME.)

DAY 1 _____

DAY 2 _____

DAY 3 _____

DAY 4 _____

DAY 5 _____

DAY 6 _____

DAY 7 _____

4. On the days that you saw your loved one, what was the most time you spent with him/her?....

Less than 1 hour	**1-4 hours**	**4-8 hours.**	**8 or more hours**	DON'T KNOW
1	2	3	4	999

5. On the days that you saw X_____, what is the least number of hours you spent with her/him in one day?.... *(DOES NOT INCLUDE DAYS NOT SEEN)*

Less than 1 hour	**1-4 hours**	**4-8 hours.**	**8 or more hours**	DON'T KNOW
1	2	3	4	999

6. In the last year, how often did you see X_____?....

Daily	**At least once a week**	**At least once a month**	**Less than once a month**	DON'T KNOW
1	2	3	4	999

7. In your opinion, how long before X_____'s death was s/he aware that s/he was dying?....

Never Aware	One week before death	2-4 weeks before death	2-6 months before death	6-12 months before death	DON'T KNOW
1	2	3	4	5	999

SCREENING QUESTION

At any time during the last seven days of X_____'s life, did s/he talk with you in a way that you could understand her/him?

1 YES → *(CONTINUE WITH LAST SEVEN DAYS INTERVIEW)*
2 NO → *(CONTINUE WITH LAST MONTH INTERVIEW)*

UNIVERSITY OF WASHINGTON SCHOOL OF MEDICINE

QODD: SIGNIFICANT OTHER
AFTER DEATH INTERVIEW

*** LAST SEVEN DAYS/LAST MONTH – PART 2 ***

PATIENT ID: ___ ___ ___

SIGNIFICANT OTHER ID: ____ ___ ____

INTERVIEW DATE ___ ___ / ___ ___ / ___ ___ ___ ___
Month **Day** **Year**

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Seven Day Version

QUALITY OF DEATH AND DYING (QODD)

The next set of questions asks about the quality of X_____'s experience of dying and death during the last seven days of her/his life.

I will ask you about a number of experiences that X_____ may have had in the last seven days of her/his life.

Each question has two parts. The first part will ask you how often X_____ experienced each item using a scale where 0 is 'none of the time' and 5 is 'all of the time'. *(SHOW CARD # 1)* **The second part will ask you to rate this aspect of X_____'s dying experience on a scale from 0 to 10, where 0 is a 'terrible experience', and 10 is an 'almost perfect experience'.** *(SHOW CARD # 2)*

Let's start with an example.

In the last seven days of her/his life, how often did X_____ listen to music?

I'd like you to use the first scale to tell me how often X_____ listened to music during the last seven days of her/his life, with 0 being "none of the time" and 5 being "most of the time".... *(POINT TO CARD WHILE READING DIRECTIONS)*

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON"T KNOW
0	1	2	3	4	5	999

Then I will ask you how YOU would rate this aspect as it relates to the quality of X_____'s dying experience. Just keep in mind that your rating response should be based on how YOU think this aspect affected the quality of her/his life during X_____'s dying experience. For this question, 0 is a "terrible experience" and 10 is an "almost perfect experience".
(POINT TO CARD WHILE READING DIRECTIONS)

Terrible Experience										Almost Perfect	DON"T KNOW
0	1	2	3	4	5	6	7	8	9	10	999

Do you have any questions before we begin?

SECTION A

During the last seven days of X_____'s life,

1a. How often did X_____ appear to have her/his pain under control?....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

2a. How often did X_____ appear to have control over what was going on around her/him?....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

3a. How often was X_____ able to feed her/himself?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

(NOTE: IF THE RESPONDENT UNDERSTANDS THE RESPONSE OPTIONS, IT IS NOT NECESSARY TO READ THEM AFTER EACH QUESTION. HOWEVER, SOME RESPONDENTS MAY NEED THE REPETITION.)

During the last seven days of X_____'s life,

4a. How often did X_____ have control of her/his bladder or bowels?....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

5a. How often did X_____ breathe comfortably?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

6a. How often did X_____ appear to feel at peace with dying?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

During the last seven days of X_____'s life,

7a. How often did X_____ appear to be unafraid of dying?....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

8a. How often did X_____laugh and smile?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

9a. How often did X_____ appear to have the energy to do most things that s/he wanted to do?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

During the last seven days of X_____'s life,

10a. How often did X_____ appear to be worried about strain on her/his loved ones?....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

11a. How often did X_____ appear to keep her/his dignity and self-respect?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

12 a,b Did X_____ have a living spouse or partner?

(IF YOU KNOW THE ANSWER TO THIS ITEM, DO NOT ASK BUT CIRCLE THE CORRECT NUMBER AND FOLLOW THE RESPONSE PATTERN).

1 YES

2 NO → *(SKIP TO QUESTION 13)*

12a. How often did X_____ spend time with her/his spouse or partner?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

During the last seven days of X_____'s life,

13a,b. Did X_____ have living children?

(IF YOU KNOW THE ANSWER TO THIS ITEM, DO NOT ASK BUT CIRCLE THE CORRECT NUMBER AND FOLLOW THE RESPONSE PATTERN).

1 YES

2 NO → *(SKIP TO QUESTION 14)*

13a. How often did X_____ spend time with her/his children?....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

14a. How often did X_____ spend time with other family and friends?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

During the last seven days of X_____'s life,

15a. How often did X_____ spend time alone?....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

16,a,b. Did X_____ have pets?

(IF YOU KNOW THE ANSWER TO THIS ITEM, DO NOT ASK BUT CIRCLE THE CORRECT NUMBER AND FOLLOW THE RESPONSE PATTERN).

1 YES

2 NO → *(SKIP TO SECTION B)*

16a. How often did X_____ spend time with pets?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

SECTION B

In this section, I won't be asking how often X_____ did a certain activity but I'll ask for a "YES" or "NO" response first. Then, I'll ask you to rate the quality of the experience with 0 indicating "a terrible experience" and 10 indicating " an almost perfect experience"

(USE CARD # 3 IF NEEDED FOR "PART A" OF EACH QUESTION; USE CARD #2 FOR "PART B")

During the last seven days of X_____'s life,

17a. Did X_____ appear to find meaning and purpose in her/his life?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 18)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 18)*

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

18a. Was X_____ touched or hugged by her/his loved ones?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 19)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 19)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

During the last seven days of X_____'s life,

19a. Did X_____ attend any important events - for example weddings, graduations, and birthdays?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 20)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 20)*

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

20a. Were all of X_____'s health care costs taken care of?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 21)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 21)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

21a. Did X_____ say goodbye to loved ones?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 22)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 22)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

During the last seven days of X_____'s life,

22a. Did X_____ have one or more visits from a religious or spiritual advisor?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 23)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 23)*

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

23a. Did X_____ have a spiritual service or ceremony before his/her death?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 24)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 24)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

24a. Was a mechanical ventilator or kidney dialysis used to prolong X_____'s life?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 25)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 25)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

25a. Did X_____ have the means to end her/his life if s/he needed to?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 26)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 26)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

26a. Did X_____clear up any bad feelings with others?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO SECTION C)*
777	REFUSED, NO RESPONSE	→ *(GO TO SECTION C)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

SECTION C

The next set of questions does not use a timeline of the last seven days of X_____'s life. Instead, these questions ask if X_____ has EVER done an activity. For the first part of the question, please answer "YES" or "NO" . For the second part of the question, please rate the quality of this aspect of X_____'s dying experience with the same rating scale we have been using, where 0 is "a terrible experience" and 10 is "an almost perfect experience".

(USE CARD #3 FOR "PART A", IF NEEDED, AND CARD #2 FOR "PART B")

27a. Did X_____ have her/his funeral arrangements in order prior to death?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 28)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 28)*

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

28a. Did X_____ discuss her/his wishes for end of life care with her/his doctor --for example, resuscitation or intensive care?

1 YES
2 NO
999 DON'T KNOW → *(GO TO SECTION D)*
777 REFUSED, NO RESPONSE → *(GO TO SECTION D)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

SECTION D

The next questions ask about where, with whom, and how X_____ died.

29a. Where did your loved one die? *(CIRCLE THE NUMBER AND FILL IN BLANKS AS NEEDED)*

1 PATIENT'S OWN HOME

2 SURROGATE'S HOME (IF OTHER THAN PATIENT'S HOME)

3 OTHER HOME
Whose home? _____

4 HOSPITAL
Which hospital? _____

5 IN-PATIENT HOSPICE
Which in-patient hospice? _____

6 NURSING HOME (OR OTHER LONG TERM CARE FACILITY)
Which nursing home or other long term care facility? _____

7 OTHER
Which other place? _____

999 DON'T KNOW → *(GO TO QUESTION 30)*

777 REFUSED, NO RESPONSE → *(GO TO QUESTION 30)*

b. How would you rate this aspect of X_____'s death?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

30a. Was anyone present at the moment of X_____'s death?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 31)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 31)*

b. How would you rate this aspect of X_____'s death?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

31a. In the moment before X_____'s death, was he/she.....

1	**Awake**	
2	**Asleep**	
3	**In a coma/unconscious**	
999	DON'T KNOW	→ *(GO TO SECTION E)*
777	REFUSED, NO RESPONSE	→ *(GO TO SECTION E)*

b. How would you rate this aspect of X_____'s death?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

SECTION E

The last two questions in this section ask for your overall rating of the last seven days of X_____'s life and her/his moment of death. *(SHOW CARD #2)*

32. How would you rate the quality of X_____'s life during the last seven days of her/his life?....

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

33. How would you rate the quality of X_____'s moment of death?....

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

Last Month Version

QUALITY OF DEATH AND DYING (QODD)

The next set of questions asks about the quality of X_____'s experience of dying and death during the last month of her/his life.

I will ask you about a number of experiences that X_____ may have had in the last month of her/his life.

Each question has two parts. The first part will ask you how often X_____ experienced each item using a scale where 0 is 'none of the time' and 5 is 'all of the time'. *(SHOW CARD # 1)* **The second part will ask you to rate this aspect of X_____'s dying experience on a scale from 0 to 10, where 0 is a 'terrible experience', and 10 is an 'almost perfect experience'.** *(SHOW CARD # 2)*

Let's start with an example.

In the last month of her/his life, how often did X_____ listen to music?

I'd like you to use the first scale to tell me how often X_____ listened to music during the last month of her/his life, with 0 being "none of the time" and 5 being "most of the time"....
(POINT TO CARD WHILE READING DIRECTIONS)

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON"T KNOW
0	1	2	3	4	5	999

Then I will ask you how YOU would rate this aspect as it relates to the quality of X_____'s dying experience. Just keep in mind that your rating response should be based on how YOU think this aspect affected the quality of her/his life during X_____'s dying experience. For this question, 0 is a "terrible experience" and 10 is an "almost perfect experience".
(POINT TO CARD WHILE READING DIRECTIONS)

Terrible Experience										Almost Perfect	DON"T KNOW
0	1	2	3	4	5	6	7	8	9	10	999

Do you have any questions before we begin?

SECTION A

During the last month of X _____'s life,

1a. How often did X_____ appear to have her/his pain under control?....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

2a. How often did X_____ appear to have control over what was going on around her/him?.....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

3a. How often was X_____ able to feed her/himself?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

(NOTE: IF THE RESPONDENT UNDERSTANDS THE RESPONSE OPTIONS, IT IS NOT NECESSARY TO READ THEM AFTER EACH QUESTION. HOWEVER, SOME RESPONDENTS MAY NEED THE REPETITION.)

During the last month of X _____'s life,

4a. How often did X_____ have control of her/his bladder or bowels?....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

5a. How often did X_____ breathe comfortably?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

6a. How often did X_____ appear to feel at peace with dying?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

During the last month of X _____'s life,

7a. How often did X_____ appear to be unafraid of dying?....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

8a. How often did X_____laugh and smile?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

9a. How often did X_____ appear to have the energy to do most things that s/he wanted to do?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

During the last month of X _____'s life,

10a. How often did X_____ appear to be worried about strain on her/his loved ones?....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

11a. How often did X_____ appear to keep her/his dignity and self-respect?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

12 a,b Did X_____ have a living spouse or partner?

(IF YOU KNOW THE ANSWER TO THIS ITEM, DO NOT ASK BUT CIRCLE THE CORRECT NUMBER AND FOLLOW THE RESPONSE PATTERN).

1 YES

2 NO → *(SKIP TO QUESTION 13)*

12a. How often did X_____ spend time with her/his spouse or partner?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

During the last month of X _____'s life,

13 a,b. Did X_____ have living children?

(IF YOU KNOW THE ANSWER TO THIS ITEM, DO NOT ASK BUT CIRCLE THE CORRECT NUMBER AND FOLLOW THE RESPONSE PATTERN).

1 YES

2 NO → *(SKIP TO QUESTION 14)*

13a. How often did X_____ spend time with her/his children?....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

14a. How often did X_____ spend time with other family and friends?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

During the last month of X_____'s life,

15a. How often did X_____ spend time alone?....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

16,a,b. Did X_____ have pets?

(IF YOU KNOW THE ANSWER TO THIS ITEM, DO NOT ASK BUT CIRCLE THE CORRECT NUMBER AND FOLLOW THE RESPONSE PATTERN).

1 YES

2 NO → *(SKIP TO SECTION B)*

16a. How often did X_____ spend time with pets?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

SECTION B

In this section, I won't be asking how often X_____ did a certain activity but I'll ask for a "YES" or "NO" response first. Then, I'll ask you to rate the quality of the experience with 0 indicating "a terrible experience" and 10 indicating " an almost perfect experience"

(USE CARD # 3 IF NEEDED FOR "PART A" OF EACH QUESTION; USE CARD #2 FOR "PART B")

During the last month of X_____'s life,

17a. Did X_____ appear to find meaning and purpose in her/his life?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 18)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 18)*

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

18a. Was X_____ touched or hugged by her/his loved ones?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 19)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 19)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

During the last month of X_____'s life,

19a. Did X_____ attend any important events - for example weddings, graduations, and birthdays?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 20)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 20)*

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

20a. Were all of X_____'s health care costs taken care of?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 21)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 21)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

21a. Did X_____ say goodbye to loved ones?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 22)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 22)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

During the last month of X_____'s life,

22a. Did X_____ have one or more visits from a religious or spiritual advisor?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 23)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 23)*

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

23a. Did X_____ have a spiritual service or ceremony before his/her death?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 24)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 24)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

24a. Was a mechanical ventilator or kidney dialysis used to prolong X_____'s life?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 25)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 25)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

25a. Did X_____ have the means to end her/his life if s/he needed to?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 26)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 26)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

26a. Did X_____clear up any bad feelings with others?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO SECTION C)*
777	REFUSED, NO RESPONSE	→ *(GO TO SECTION C)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

SECTION C

The next set of questions does not use a timeline of the last month of X_____'s life. Instead, these questions ask if X_____ has EVER done an activity. For the first part of the question, please answer "YES" or "NO" . For the second part of the question, please rate the quality of this aspect of X_____'s dying experience with the same rating scale we have been using, where 0 is "a terrible experience" and 10 is "an almost perfect experience".

(USE CARD #3 FOR "PART A", IF NEEDED, AND CARD #2 FOR "PART B")

27a. Did X_____ have her/his funeral arrangements in order prior to death?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 28)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 28)*

b. How would you rate this aspect of X_____'s dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

28a. Did X_____ discuss her/his wishes for end of life care with her/his doctor --for example, resuscitation or intensive care?

1 YES
2 NO
999 DON'T KNOW → *(GO TO SECTION D)*
777 REFUSED, NO RESPONSE → *(GO TO SECTION D)*

b. How would you rate this aspect of X_____'s dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

SECTION D

The next questions ask about where, with whom, and how X_____ died.

29a. Where did your loved one die? *(CIRCLE THE NUMBER AND FILL IN BLANKS AS NEEDED)*

8 PATIENT'S OWN HOME

9 SURROGATE'S HOME (IF OTHER THAN PATIENT'S HOME)

10 OTHER HOME
Whose home? _____

11 HOSPITAL
Which hospital? _____

12 IN-PATIENT HOSPICE
Which in-patient hospice? _____

13 NURSING HOME (OR OTHER LONG TERM CARE FACILITY)
Which nursing home or other long term care facility? _____

14 OTHER
Which other place? _____

999 DON'T KNOW → *(GO TO QUESTION 30)*

777 REFUSED, NO RESPONSE → *(GO TO QUESTION 30)*

b. How would you rate this aspect of X_____'s death?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

30a. Was anyone present at the moment of X_____'s death?

1	YES	
2	NO	
999	DON'T KNOW	→ *(GO TO QUESTION 31)*
777	REFUSED, NO RESPONSE	→ *(GO TO QUESTION 31)*

b. How would you rate this aspect of X_____'s death?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

31a. In the moment before X_____'s death, was he/she.....

1	**Awake**	
2	**Asleep**	
3	**In a coma/unconscious**	
999	DON'T KNOW	→ *(GO TO SECTION E)*
777	REFUSED, NO RESPONSE	→ *(GO TO SECTION E)*

b. How would you rate this aspect of X_____'s death?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

SECTION E

The last two questions in this section ask for your overall rating of the last month of X_____'s life and her/his moment of death. *(SHOW CARD #2)*

32. How would you rate the quality of X_____'s life during the last month of her/his life?....

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

33. How would you rate the quality of X_____'s moment of death?.....

Terrible Experience										**Almost Perfect**	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

DID YOU USE THE VERBAL CUE CARDS FOR THE QODD?

1 YES
2 NO

CONCLUDING ITEMS FOR BOTH SEVEN DAY AND LAST MONTH

SIGNIFICANT OTHER DEMOGRAPHICS

For the final part of the interview, I would like to ask you a few questions about yourself.

1. What is your relationship to X _____? (*CIRCLE ONE NUMBER*)

1 SPOUSE/PARTNER
2 CHILD
3 SIBLING
4 FRIEND
5 PARENT
6 OTHER RELATIVE
7 OTHER

What other relationship?_____

2. What is your birthdate? ____ ____/____ ____/____ ____ ____ ____
MONTH DAY YEAR

3. How long does it take you to get to X_____'s home?

(ENTER 00/00 FOR HOUR/MINUTES IF SURROGATE LIVES W/PATIENT)

_____ _____ / _____ _____
HOURS MINUTES

4. How long have you known X_____?

_____ _____/_____ _____
YEARS MONTHS

5. *(NOTE THE SURROGATE'S GENDER AND CIRCLE THE CORRECT NUMBER)*

1 FEMALE
2 MALE

6. What is your race or ethnicity? (*CIRCLE ALL THAT APPLY*)

YES	NO	
1	2	NON-HISPANIC WHITE
1	2	BLACK OR AFRICAN AMERICAN
1	2	HISPANIC
1	2	ASIAN OR PACIFIC ISLANDER
1	2	NATIVE AMERICAN
1	2	OTHER _____

(FILL IN IF 'OTHER' SPECIFIED)

7. What is the highest year of schooling you have completed? (*CIRCLE ONE*)

1 NO FORMAL SCHOOL
2 KINDERGARTEN THRU GRADE 8
3 SOME HIGH SCHOOL
4 HIGH SCHOOL DIPLOMA OR G.E.D.
5 SOME COLLEGE
6 4-YEAR COLLEGE DEGREE (B.A., B.S.)
7 GRADUATE OR PROFESSIONAL SCHOOL

We are now finished with the interview. Thank you for your time in answering all of my questions.

NOTE: STOP TIME_____:_____.

INTERVIEWEE ASSESSMENT

We are now finished with the formal part of the questionnaire. For these last questions, we are looking for your help to guide us in future research. We are interested in your impressions in your own words.

1. Would you like to continue?

1 YES
2 NO

2. Overall, how much of a burden on you was this questionnaire?....

No Burden at all					Moderate Burden					Terrible Burden
0	1	2	3	4	5	6	7	8	9	10

3. Is there anything about the quality of X_____'s death that we should have asked but didn't?

(PROBES: WAS THERE ANYTHING ELSE THAT WAS IMPORTANT IN THE LAST SEVEN DAYS OR LAST MONTH OF LIFE THAT WE DIDN'T ASK ABOUT? IS THERE ANYTHING ELSE YOU THINK WE SHOULD KNOW ABOUT THAT HAPPENED TO YOUR LOVED ONE DURING HIS/HER LAST WEEK/LAST MONTH OF LIFE THAT COULD HAVE BEEN IMPROVED?)

_____

_____

_____

_____

_____

4. Is there anyway that we could have made this questionnaire easier on you?

(PROBES: WOULD IT HAVE BEEN BETTER TO WAIT LONGER BEFORE WE COMPLETED THIS WITH YOU? WOULD IT HAVE BEEN BETTER TO DO IT EARLIER? SHOULD WE HAVE ASKED THE QUESTIONS IN A DIFFERENT WAY?)

_____

_____

_____

_____

Do you have any other questions or comments for us?

Thank you again for your help. We appreciate your time and willingness to help us improve experiences at the end of life.

INTERVIEWER ASSESSMENT

THE FOLLOWING SECTION IS TO BE COMPLETED AFTER EVERY INTERVIEW BY THE INTERVIEWER.

CIRCLE THE NUMBER OF THE BEST ANSWER FOR EACH QUESTION

1. Was the interview complete?

1 YES
2 NO

2. If NO, Please note reason(s):

YES	NO	
1	2	RESPONDENT'S ILLNESS
1	2	RESPONDENT'S FATIGUE
1	2	RESPONDENT'S POOR MENTAL STATUS
1	2	RESPONDENT'S UNCOOPERATIVENESS
1	2	RESPONDENT INSULTED, UPSET BY QUESTIONS
1	2	UNSATISFACTORY INTERVIEW CONDITIONS

3. Rate the quality of data

1 POOR ⟶ PLEASE COMMENT ON OTHER SIDE/BELOW
2 FAIR ⟶ PLEASE COMMENT ON OTHER SIDE/BELOW
3 GOOD

3b. Comments

4. This interview was conducted:

1 IN PERSON
2 BY TELEPHONE

5. This interview was conducted by:

INTERVIEWER'S NAME: _____

UNIVERSITY OF WASHINGTON SCHOOL OF MEDICINE

QODD
QODD Response Cards
AFTER-DEATH INTERVIEW

NOTE: Cards are produced as single pages so they can be laminated and presented to patients. Card number is at bottom left of page.

NONE OF THE TIME	A LITTLE OF THE TIME	SOME OF THE TIME	A GOOD BIT OF THE TIME	MOST OF THE TIME	ALL OF THE TIME
0	1	2	3	4	5

Card 1

Terrible Experience	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect Experience

Card 2

YES	**1**
NO	**2**

Card 3

Terrible Experience			Poor			Neither Good Nor Bad			Good			Almost Perfect Experience
0	1	2	3	4	5	6	7	8	9	10		

Card 2: Verbal Cue Card

QUALITY OF LIFE INVENTORY

The QOLI assesses an individual's quality of life through self-report of the importance they attach to each of 16 life domains (on a 3-point rating scale) as well as their current satisfaction with each domain (on a 6-point rating scale). Importance scores are multiplied by satisfaction scores for each domain, and then these scores are summed to determine an overall current quality of life for each individual. This measure is very quick to complete, and has been normed in a community sample of adults. It has also been used to track changes in individuals over the course of therapy. Higher scores indicate a higher overall quality of life.

Abbreviated Name: QOLI
Author(s): Michael B. Frisch
Purpose: To measure life satisfaction and outcome with a single score based on 16 key areas of life including love, work and recreation and to show problems in living and strength in each of the 16 areas.
Population: Adult and adolescent
Age Range : 12 years and up
Type of Instrument: Life satisfaction and Health-Related Quality of Life
Mode of Administration:

Rater:	Self-/ Interviewer-administered
Time required:	3 min for computer version and 5 min for hand scored version of test
Response Options:	3-point Likert scale
Scoring:	Global score: minimum score/maximum score: -6 to 6 OR T scores from 0 to 76 Scores by dimension
Score Direction:	Higher scores show better QoL
Weighting:	Yes

Number of Items: 32
Original Language: English

Copyright: 1994 Michael B. Frisch and National Computer Systems, Inc

Contact for information and permission to use:

NCS Assessments:
Phone: 1-800-627-7271, ext. 5151
Phone: 1- 952-939-5151
Fax: 1-800-632-9011
E-Mail: assessment@ncs.com

Dimensions covered by the questionnaire :

16 areas or domains of life satisfaction with two questions for each domain. One question assesses the importance of the domain, the second assesses the satisfaction with the domain. The product of these answers is used in scoring. The product is called the Weighted Satisfaction Rating.

- Health
- Self-esteem
- Goals and values
- Money
- Work
- Play
- Learning
- Creativity
- Helping
- Love
- Friends
- Children
- Relatives
- Home
- Neighbohood
- Community
- The results also includes an Overall score

Key References:

1. Frisch, M.B. (1994). Quality of Life Inventory(QOLI). Minneapolis, MN: National Computer Systems.

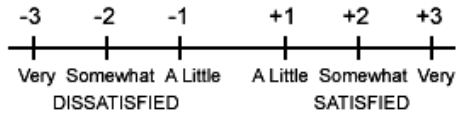
QUALITY OF LIFE INVENTORY

QUALITY OF LIFE INVENTORY by Michael B. Frisch, PhD

HEALTH is being physically fit, not sick, and without pain or disability.

1. How important is HEALTH to your happiness?

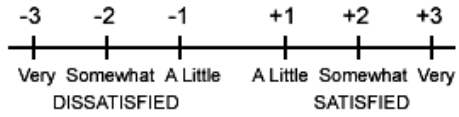
2. How satisfied are you with your HEALTH?



SELF-ESTEEM means liking and respecting yourself in light of your strengths and weaknesses, successes and failures, and ability to handle problems.

3 How Important is SELF-ESTEEM to your happiness?

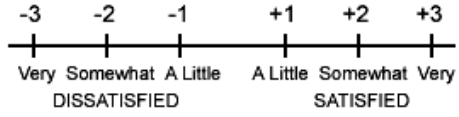
4. How satisfied are you with your SELF-ESTEEM?



GOALS-AND-VALUES are your beliefs about what matters most in life and how you should live, both now and in the future. This includes your goals in life, what you think is right or wrong, and the purpose or meaning of life as you see it.

5. How important are GOALS-AND-Values to your happiness?

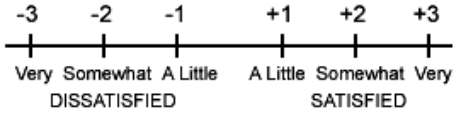
6. How satisfied are you with your GOALS-AND-VALUES?



MONEY is made up of three things. II is the money you earn, the things you own (like a car or furniture), and believing that you will have the money and things that you need In the future.

7. How important is MONEY to your happiness?

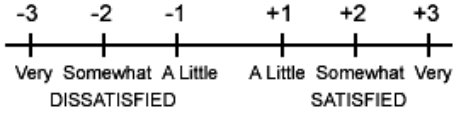
8. How satisfied are you with the MONEY you have?



WORK means your career or how you spend most of your time. You may work at a job, at home taking care of your family, or at school as a student. WORK Includes your duties on the job, the money you earn (if any), and the people you work with. (If you are unemployed, retired, or can't work, you can still answer these questions.)

9. How important is WORK to your happiness?

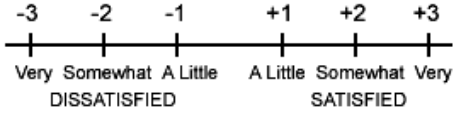
10. How satisfied are you with your WORK? (if you are not working, say how satisfied you are about not working)



PLAY is what you do in your free time to relax, have fun, or improve yourself This could include watching movies, visiting friends, or pursuing a hobby like sports or gardening.

11. How Important is PLAY to your happiness?

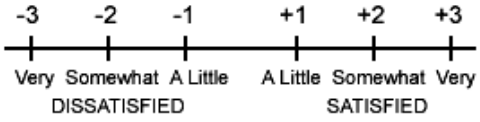
12. How satisfied ere you with the PLAY in your life?



LEARNING means gaining new skills or information about things that interest you. LEARNING can come from reading books or taking classes on subjects like history, car repair, or using a computer.

13. How important is LEARNING to your happiness?

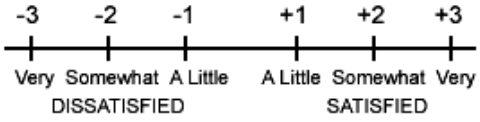
14. How satisfied are you with your LEARNING?



CREATIVITY is using your imagination to come up with new and clever ways to solve everyday problems or to pursue a hobby like painting, photography, or needlework. This can include decorating your home, playing the guitar, or finding a new way to solve a problem at work.

15. How important is CREATIVITY to your happiness?

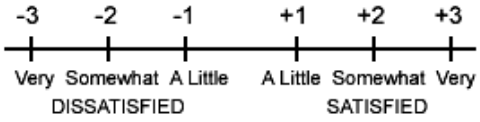
16. How satisfied are you with your CREATIVY?



HELPING means helping others in need or helping to make your community a better place to live. HELPING can be done on your own or in a group like a church, a neighbourhood association, or a political party. HELPING can include doing volunteer work at a school or giving money to a good cause HELPING means helping people who are not your friends or relatives.

17. How Important is HELPING to your happiness?

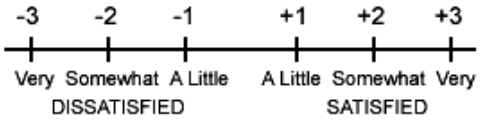
18. How satisfied are youu with the HELPING you do?



LOVE is a very close romantic relationship with another person LOVE usually includes sexual feelings and feeling loved, cared for, and understood (if you do not have a LOVE relationship, you can still answer these questions.)

19. How important is LOVE to your happiness?

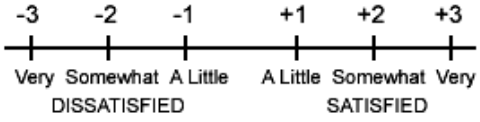
20. How satisfied are you with the LOVE in your life? (If you are not in a LOVE relationship, say how satisfied you feel about not having a LOVE relationship.)



FRIENDS are people (not relatives) you know well and care about who have interests and opinions like yours. FRIENDS have fun together, talk about personal problems, and help each other out. (if you have no FRIENDS. you can still answer these questions.)

21. How important are FRIENDS to your happiness?

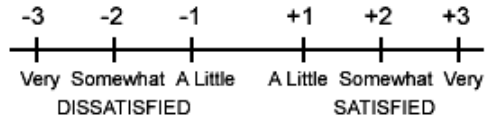
22. How satisfied are you with your FRIENDS? (If you have no FRIENDS, say how satisfied you are about having no FRIENDS.)



CHILDREN means how you get along with your child (or children) Think of how you get along as you care for, visit, or play with your child. (If you do not have CHILDREN, you can still answer these questions.)

23. How important are CHILDREN to your happiness? (If you have no CHILDREN, say how important having a child is to your happiness)

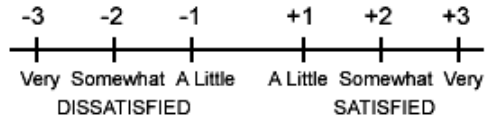
24. How satisfied are you with your relationships with your CHILDREN? (If you have no CHILDREN, say how satisfied you feel about not having children)



RELATIVES means how you get along with your parents, grandparents, brothers, sisters, aunts, uncles, and in-laws Think about how you get along when you are doing things together like visiting, talking on the telephone, or helping each other out. (If you have no living RELATIVES, blacken the 0 ("Not Important circle for question 25 and do not answer question 26.)

25. How important are RELATIVES to your happiness?

26. How satisfied are you with your relationships with RELATIVES?

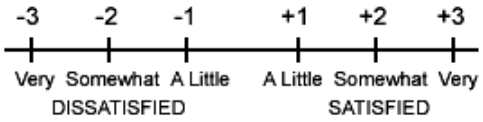


Adult Learner Code _____
Date: _____
Interviewer's Initials _____

HOME is where you live. It is your house or apartment and the yard around it Think about how nice it looks, how big it is, and your rent or house payment.

27. How important is your HOME to your happiness?

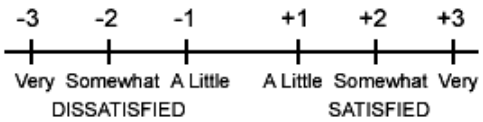
28. How satisfied are you with your HOME?



NEIGHBORHOOD is the area around your home. Think about how nice it looks, the amount of crime in the area, and how well you like the people

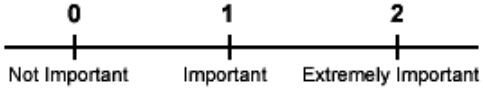
29. How important is your NEIGHBORHOOD to your happiness?

30. How satisfied are you with your NEIGHBORHOOD?

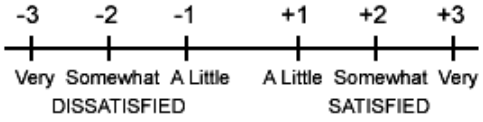


COMMUNITY is the whole city, town, or rural area where you live (it is not just your neighbourhood). COMMUNITY includes how nice the area looks, the amount of crime, and how well you like the people. It also includes places to go for fun like parks, concerts, sporting events, and restaurants. You may also consider the cost of things you need to buy, the availability of jobs, the government, schools, taxes, and pollution.

31. How important is your COMMUNITY to your happiness?



32. How satisfied are you with your COMMUNITY?



QUALITY OF LIFE MEASURE FOR CHILDREN AGED 3-8 YEAR OLDS

Quality of Life Measure for Children aged 3-8 year olds (TedQL) is a self-report measure includes 30 items divided into three domains (ability, social, and mood). A force recognition task is used in which two bears are described in relation to each item, then children are asked to choose 'which bear was most like them' (actual self). Following initial selection of either bear, children probe for whether they are 'really like this' or 'just a little bit'. Children are then asked: 'what they would like to be like' if they change how they are at any give activity (ideal self).

Abbreviated Name: TedQL
Author(s): Joanne Lawford (Cremeens), Christine Eiser
Purpose: To assess health-related quality of life in children aged 3-8 years
Population: Pediatrics
Age Range : 5 to 8 years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-/ proxy-administered
Time required:	11 minutes
Response Options:	Likert scale - Supported by thermometer scale
Scoring:	Global score: Minimum score: 0 / Maximum score: 88
Score Direction:	Higher scores show better QoL

Number of Items: 22
Original Language: English

Contact for information and permission to use:

Joanne Cremeens
St. Jude Children's Research Hospital
332 N. Lauderdale
Memphis, TN 38105
Phone: 1-(901) 495-3300
Fax: 1-(901) 495-4011
Email: Joanne.Cremeens@stjude.org

Dimensions covered by the questionnaire :

22 items, no domains

Key References:

1. Lawford J, Volavka N, Eiser C. A generic measure of Quality of Life for children aged 3-8 years: results of two preliminary studies. Pediatr Rehabil 2001; 4:197-207.

Preliminary findings from the development of a new quality of life (QoL) measure for children aged 3-8 years are presented in two studies. Thirty-six children (5-6 years) completed a 10-item measure in Study 1, which included ratings of their abilities and 'happiness'. The children also completed an established QoL measure and 24 parents completed a proxy QoL measure. Preliminary support for the face and construct validity of the new measure is reported. There were correlations between the children's scores on the two measures ($p < 0.05$). However, child and parent scores were not correlated ($p = 0.65$). Twenty-four children (3-4 years) completed a modified version of the new QoL measure in Study 2, which consisted of 23 items. The internal reliability of the measure and the speed of children's responses allowed comparison of the efficacy of two response formats. Significant differences in speed were found in children's responses using different response formats, and differences in the internal consistency of the measure. Eighteen parents completed a proxy QoL measure, as in Study 1. Child and parent scores on the two measures were not correlated ($p = 0.23$). These studies highlight the difficulties in obtaining self-report QoL data from children below 5 years.

Domains and items within the TedQL and TedQL.2 measures

Domain	*Items on TedQL*	*Items on TedQL.2*
Physical competence	Good at running Good at swimming	Good at swinging Good at running Good at playing with balls Can climb high things Can tie shoes Good at hopping
Peer acceptance	Has got lots of friends Gets teased at school (N)	Has lots of friends Likes to play with friends Likes to tell friends what to do (N) Has friends to play with (others like playing with them)
Maternal acceptance	Mum/dad tells them off a lot (N) Goes on trips with mum/dad	Likes to play with their mum Mum talks to them Likes to tell mum what been doing Mum tells them off a lot (N)
Psychological functioning	Gets really cross (N) Has a lot of really bad dreams at night (N)	Is happy Has bad dreams at night (N) Worries about losing their things (N) Some things make them really cross (N)
Cognitive functioning	Really good at reading Remembers what teacher asks him/her to do	Gets upset if can't do their work Remembers what people tell them to do Good at reading Good at writing Getting better at drawing

(N) = negatively scored item, scores were reversed.

Description of the measure, and psychometric validation and development:

The TedQL measure has been developed over a series of studies for the primary author's PhD thesis. While the earlier versions (versions 1 and 2) show relatively low reliability coefficients, later versions did show an improvement in reliability values and also evidence for convergent validity when compared to the PedsQL^{TM}4.0 measure (Cremeens et al., in preparation). These further studies are currently being prepared for publication, following the successful completion of the author's PhD thesis examination. The TedQL.4 also contains a parent proxy report version, which can be completed by parents in parallel to the child version. Within our studies, we investigated the impact of different response scale types (facial expression, circular, and thermometer) on children's responses to the TedQL.3 items, to establish the most appropriate scale for use with our measure (Cremeens, in press). We compared the psychometric properties of our measure (internal and test-retest reliability, item-total correlations, ceiling and floor effects, % of DK answers) across these three scale types (Cremeens et al., in press).

The TedQL.4 measure (child and parent versions) contains 22 items, answered on a 4-point thermometer scale (Cremeens, 2004). The items within the measure are listed below:

T1: good at swinging
T2: playing ball games
T3: good at climbing high things
T4: good at running
T5: good at bike riding
T6: having friends to play with
T7: friends coming over to their house
T8: friends teasing them (N)
T9: mum/dad playing with them at home
T10: telling mum/dad what been doing at school
T11: playing with siblings
T12: siblings bossing them (N)
T13: seeing grandparents
T14: getting told off at home (N)
T15: feeling scared (N)
T16: having bad dreams at night (N)
T17: getting cross/angry (N)
T18: worrying about losing things (N)
T19: doing mathematics/numbers
T20: writing
T21: drawing
T22: reading

Internal reliability values for TedQL.4:
Cronbach alpha's ranged from 0.53 to 0.75 (Cremeens et al., in press).
Test-retest reliability values for TedQL.3:
ICC's ranged from 0.50 to 0.80 (Cremeens et al., in press).
Convergent validity correlations between child TedQL.4 and child PedsQL scores:
Correlation coefficients ranged from 0.40 to 0.70 (Cremeens et al., in press).

Summary of alterations made to the TedQL measure as a result of additional studies:

In additional studies, we compared the psychometric properties of children's responses when answering TedQL.3 items across three different scales. Contrary to our predictions, children using the *thermometer* response scale produced the 'best' psychometric properties for the measure, although the results were somewhat mixed (Cremeens et al., in press). Children using the thermometer scale showed some of the highest internal consistency ratings, and the highest reproducibility of responses over time (Cremeens et al., in press). The children themselves also preferred this scale to the circles and faces scales (Cremeens et al., in press). Therefore we decided that the thermometer scale would be used to represent the response choices to children for the new version of our measure (TedQL.4).

Researchers in the social attitude field have suggested that the response scale should be matched to the type of question, i.e., that bipolar scales are more suited to questions rating attitudes which fall clearly onto two sides; and linear scales are more suited to questions rating abilities, e.g., from good to not good (Schwartz & Oyserman, 2001, Schwartz et al., 1998, Schwartz & Sudman, 1995). The type of response scale (e.g., bipolar or continuous) gives information about the focus of the items. As such scale type may influence how the respondent views the attribute in question, or how they report the frequency of their behaviours (Knauper & Turner, 2003). The meaning conveyed by the scales used in a response scale needs to match the types of items being rated (McLaughlin, 1999). Following this rationale, the thermometer response scale would be more suited to the TedQL.4 items which ask children to rate how 'good' they are at given skills or how 'much' they feel something (Cremeens et al., in preparation). We felt that using the thermometer scale for these question types could help younger children to make sense of the question and make the rating task easier for them (Cremeens et al., in preparation).

Originally our measure was administered using two teddy bears to illustrate either side of the item to children, and children were required to choose which bear was most like them (i.e., either 'Iggy' or 'Ziggy'), and then they had to rate whether they were *a lot* like this or *just a little bit* (Cremeens, 2004). We felt that children would benefit from having teddy bears to represent all *four* response choices on the TedQL.4 measure (i.e., four teddy bears as opposed to two, Cremeens et al., in preparation). We chose four identical teddy bears, which could only be identified as different by their badges – four different shapes: circle, square, triangle, and diamond (see figure below, (Cremeens et al., in preparation). We introduced this change into the new version of our measure (TedQL.4).

Photograph of the four teddy bears (TedQL.4)

QUALITY OF LIFE PROFILE FOR THE CHRONICALLY ILL

Quality of Life Profile for the Chronically Ill (PLC) have been developed by Dr. Siegrist. Original instruments have been published in German. The purpose of this instrument is to assess Quality of Life in chronically ill patients. The PLC 7-dimensional, generic measure of HRQOL for adults.

Abbreviated Name: PLC
Author(s): Prof.Dr.J. Siegrist
Purpose: To assess Quality of Life in chronically ill patients
Population: Adult
Age Range : 20 to 80 years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-administered
Time required:	15-20 minutes
Response Options:	5-point Likert scale
Scoring:	Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: Core modules: 40 items
Original Language: German
Existing Translations : Spanish

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Contact for information and permission to use:

Prof. Dr.Johannes Siegrist
Department of Medical Sociology
University of Düsseldotf
PO 101007
D-40001
Phone: +49-211-81-14360
Fax: +49-211-81-12390
E-mail: siegrist@uni-duesseldorf.de

Beltz Test GmbH
Po 3751
37027 Göttingen, Germany

Dimensions covered by the questionnaire :

- Physical Functioning (8 items)
- List of Symptoms (disease specific)
- Psychological Functioning (8 items)
- Positive Mood (5 items)
- Negative Mood (8 items)
- Social Functioning (6 items)
- Social Well-being (5 items)

Key References:

1. Siegrist J, Hernandez-Mejia R, Fernandez-Lopez JA. Profile of quality of life in the Chronically Ill (PCL). Quality of Life Newsletter 2000;25:18-18
2. Siegrist J, Starke D, Laubach W, Braher E (2000). Soziale Lage und gesundheitsbezogene Lebensqualität. In: Bulliner M, Siegrist J, Rabens-Sieber (eds): Lebensqualitätsforschung aus medizinpsychologischer und -soziologischer Sicht. Jahrbuch der Medizinischen Psychologie 18, Hogrefe, Göttingen, S. 307-317.
3. Siegrist J, Broer.M, Junge.A (1996). Profile der Lebensqualität chronisch Kranker. Manual. Beltz Test, Göttingen.

In welchem Maße fühlen Sie sich gerade....

	gar nicht	etwas	mäßig	stark	sehr stark
traurig und niedergeschlagen?	0	1	2	3	4
aufmerksam und konzentriert?	0	1	2	3	4
nervös und aufgeregt?	0	1	2	3	4
gut gelaunt und guter Dinge?	0	1	2	3	4
teilnahmslos und gleichgültig?	0	1	2	3	4
beunruhigt und besorgt?	0	1	2	3	4
aktiv und voller Energie?	0	1	2	3	4
ausgeglichen und entspannt?	0	1	2	3	4
erschöpft und matt?	0	1	2	3	4
gereizt und ärgerlich?	0	1	2	3	4
ängstlich und bedroht?	0	1	2	3	4
verzweifelt und hoffnungslos?	0	1	2	3	4
hoffnungsvoll und zuversichtlich?	0	1	2	3	4

In welchem Maße fühlen Sie sich jetzt....

	gar nicht	etwas	mäßig	stark	sehr stark
traurig und niedergeschlagen?	0	1	2	3	4
aufmerksam und konzentriert?	0	1	2	3	4
nervös und aufgeregt?	0	1	2	3	4
gut gelaunt und guter Dinge?	0	1	2	3	4
teilnahmslos und gleichgültig?	0	1	2	3	4
beunruhigt und besorgt?	0	1	2	3	4
aktiv und voller Energie?	0	1	2	3	4
ausgeglichen und entspannt?	0	1	2	3	4
erschöpft und matt?	0	1	2	3	4
gereizt und ärgerlich?	0	1	2	3	4
ängstlich und bedroht?	0	1	2	3	4
verzweifelt und hoffnungslos?	0	1	2	3	4
hoffnungsvoll und zuversichtlich?	0	1	2	3	4

Wie wirkte der Patient auf Sie?

	gar nicht	etwas	mäßig	sehr	sehr stark
aufmerksam und konzentriert	0	1	2	3	4
nervös und aufgeregt	0	1	2	3	4
verzweifelt und hoffnungslos	0	1	2	3	4
beunruhigt und besorgt	0	1	2	3	4
gereizt und ärgerlich	0	1	2	3	4
aktiv am Gespräch teilnehmend	0	1	2	3	4

Cover sheet – Instructions to patients

Dear patient,

please answer all of the questions according to how you really feel. Unless otherwise indicated, please check only one answer. If you have difficulty deciding between two answers, choose the one which you feel is the most accurate (please do not make marks between the numbers).

In general, the questions have the following form:

Example.: Have you managed, in the last 7 days, to meet all the demands placed upon you at work or at home?

not at all	poorly	moderately	well	very well
0	1	2	3	4

Apply your answer – unless otherwise indicated –
to the past 7 days.

Your information will, of course, be treated confidentially and will be assessed with no name attached to it. Only your physician knows your patient's code.

Thank you for your cooperation!

Core module – quality of life

Overall in the past 7 days, how much have you felt
L1 limited in your capabilities? (*)

not at all	a little	moderately	very much	considerably
0	1	2	3	4

Have you managed, in the past 7 days....

L2 to meet all the demands placed upon you at work or at home

not at all	poorly	moderately	well	very well
0	1	2	3	4

L3 to carry out physically demanding activities

not at all	poorly	moderately	well	very well
0	1	2	3	4

L4 to concentrate throughout the day

not at all	poorly	moderately	well	very well
0	1	2	3	4

L5 to put up with hectic situations and stress in your day-to-day activities

not at all	poorly	moderately	well	very well
0	1	2	3	4

L6 to engage in your hobbies

not at all	poorly	moderately	well	very well
0	1	2	3	4

L7 to rouse yourself to do something

not at all	poorly	moderately	well	very well
0	1	2	3	4

Have you managed, in the past 7 days...

L8 to relax without your thoughts racing

not at all	poorly	moderately	well	very well
0	1	2	3	4

L9 to put aside your worries and fears

not at all	poorly	moderately	well	very well
0	1	2	3	4

L10 to have a healthy appetite

not at all	poorly	moderately	well	very well
0	1	2	3	4

L11 to sleep well at night

not at all	poorly	moderately	well	very well
0	1	2	3	4

L12 to enjoy or take pleasure in something

not at all	poorly	moderately	well	very well
0	1	2	3	4

L13 to take an interest in something

not at all	poorly	moderately	well	very well
0	1	2	3	4

L14 to maintain contact with friends and acquaintances

not at all	poorly	moderately	well	very well
0	1	2	3	4

L15 to provide help and support to others

not at all	poorly	moderately	well	very well
0	1	2	3	4

Have you managed, in the past 7 days...

L16 to let others know what bothers you

not at all	poorly	moderately	well	very well
0	1	2	3	4

L17 to take an interest in the concerns of other people

not at all	poorly	moderately	well	very well
0	1	2	3	4

L18 to do activities with other people

not at all	poorly	moderately	well	very well
0	1	2	3	4

L19 to have your wishes and needs met

not at all	poorly	moderately	well	very well
0	1	2	3	4

L20 to make your very own contribution to improving your well-being

not at all	poorly	moderately	well	very well
0	1	2	3	4

L21 to put up with everyday irritations and disappointments

not at all	poorly	moderately	well	very well
0	1	2	3	4

To what extent have you felt, in the past 7 days...

L22 sad and downhearted (*)

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L23 vigilant and focused

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L24 nervous and excited (*)

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L25 in a good mood and in good spirits

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L26 indifferent and unconcerned (*)

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L27 worried and preoccupied (*)

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L28 active and full of energy

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L29 well-balanced and relaxed

not at all	a little	moderately	very much	considerably
0	1	2	3	4

To what extent have you felt, in the past 7 days...

L30 exhausted and weak (*)

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L31 irritated and angry (*)

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L32 fearful and threatened (*)

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L33 desperate and hopeless (*)

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L34 hopeful and confident

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L35 lonely, even when you had company (*)

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L36 really close to someone with whom you are well acquainted

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L37 well and belonging to your family or friends

not at all	a little	moderately	very much	considerably
0	1	2	3	4

How much have you had, <u>in the past 7 days...</u>

L38 the impression that others were distancing themselves from you (*)

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L39 the feeling of being taken seriously and understood

not at all	a little	moderately	very much	considerably
0	1	2	3	4

L40 the feeling that everything was just getting too exhausting for you (*)

not at all	a little	moderately	very much	considerably
0	1	2	3	4

Subscales and scale construction
The scale construction is simply done by computing the mean values for each subscale.

Notice that the questions marked with an (*) has to be recoded before adding it to the scales: (0=4, 1=3, 2=2, 3=1, 4=0)

1. physical functioning: Items 1*+2+3+4+5+6+7+40* divided by the number of items=8 (Range 0-32)
2. psychological well-being:
   subscale1 negative mood: Items 22*+24*+26*+27*+30*+31*+32*+33* / 8
   subscale2 positive mood: Items 23,25,28,29,34 / 5
3. psychological functioning: Items 8,9,10,11,12,19,20,21 / 8
4. social well-being: Items 35*,36,37,38*,39 / 5
5. social functioning: Items 13,14,15,16,17,18 / 6

QUALITY OF LIFE QUESTIONNAIRE-EVANS

The Quality of Life Questionnaire (QLQ) was developed to provide a direct measure of life quality based on an individual's response to several ecological domains. In contrast to other similar measures, the QLQ's approach is based on the assumption that certain actions or behaviors of an individual in response to particular environmental situations can be considered to represent a good or poor quality of life. The QLQ was designed to provide a multidimensional measure of an individual's behavior in response to the ecological domains to which the individual interacts. It consists of 5 major domains, 15 content scales, and a social desirability scale. The QLQ also provides an overall Quality of Life Score.

The QLQ may be used to measure the relationships between quality of life and other behaviors related to physical health, psychological health, and substance abuse. It may also be useful as an evaluative measure of the impact of programs and changes in services upon both community and individual life quality. Studies indicate that quality of life measures may be useful in helping to identify community needs for improving mental health services, obtaining funding for needed programs, and promoting quality of life in general. In clinical practice, measuring quality of life is an important way to evaluate the effectiveness of group or individual therapy, drug therapy, or family therapy treatment programs. In order to alleviate specific physical or psychological symptoms, the QLQ may be used to suggest areas of an individual's life that may benefit from modification. As well, its efficient design makes the QLQ an ideal screener for employee assistance, wellness, stress, weight control, or any other programs in which people Desire change

Abbreviated Name: QLQ-E
Author(s): David R Evans, Wendy E. Cope
Purpose: To assess the quality of an individual's life across a broad range of specific areas
Population: Adult
Age Range : 18 years and up
Type of Instrument: Quality of Life
Mode of Administration:

Rater:	Self-administered
Time required:	30 minutes
Response Options:	True/False
Scoring:	Global score: Minimum score: 0 / Maximum score: 180 Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 192
Original Language: English

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Multi-Health Systems Inc.
P.O. Box 950
North Tonawanda, NY
14120-0950 USA
Phone: 1-800-456-3003
Fax: 1-800-540-4484
Email: customerservice@mhs.com

Dimensions covered by the questionnaire :

- General Well-Being (36 items) :
  - Physical Well-Being (12 items)
  - Material Well-Being (12 items)
  - Personal Growth (12 items)
- Interpersonal Relations (48 items)
  - Marital Relations (12 items)
  - Parent-Child Relations (12 items)
  - Extended Family Relations (12 items)
  - Extramarital Relations (12 items)
- Organizational Activity (24 items)
  - Altruistic Behavior (12 items)
  - Political Behavior (12 items)
- Occupational Activity (36 items)
  - Job characteristics (12 items)
  - Occupational Relations (12 items)
  - Job Satisfiers (12 items)
- Leisure and Recreational Activity (36 items)
  - Creative / Aesthetic Behavior (12 items)
  - Sports Activity (12 items)
  - Vacation Behavior (12 items)
- Social Desirability (12 items)

Key References:

1. Evans DR, Burns JE, Robinson W.E, Garrett O.J. The Quality of Life Questionnaire: A multidimensional measure. American Journal of Community Psychology. 1985; 13:305-322

This questionnaire includes a series of statements. Read each statement and answer each one TRUE or FALSE. If a statement is descriptive of you, or if you agree with it, circle TRUE (T). If a statement is not descriptive of you, or if you do not agree with it, circle FALSE (F). Answer each item so that your answer reflects your situations (that is, your feelings, activities, and views) at the present time. If an item does not apply to you put an horizontal line through both the T and F responses for that item (T F) and go on to the next question. Remember that all questions pertain to you only.

1. **Jealousy rarely affects the relationship between my partner and I.**
2. **My work is rarely boring.**
3. **I seem to be always in a hurry.**
4. **I often tell my child(ren) how much I care for them.**
5. **I support my favorite political candidate during a campaign (e.g. poster on lawn, bumper sticker, wear buttons, etc.).**
6. **My work supervisor often gives me feedback that helps me improve the quality of my work.**
7. **I usually end each day with a sense of accomplishment.**
8. **I don't keep up with the sports news.**
9. **My income limits the choice of where I can live.**
10. **I wish that the place where I work had a better reputation.**

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11. I am so busy I rarely get to go to any cultural activities (e.g. theater, museums, concerts, etc.).
12. I don't know who the political representatives for my area are.
13. I find it easy to make other people laugh.
14. There are few people whom I would consider to be good friends of mine.
15. I often spend my holidays working around the house and yard rather than going away.
16. Often I just have to get away from my home because it is too crowded and confined.
17. My partner and I seldom have time by ourselves.
18. Where I work people rarely quit their job.
19. I usually find out about good plays, movies and concerts after they are over.
20. Most people would consider me to be of average weight for my build.
21. My supervisor acts as though he/she is a better person than I.
22. There are lots of things I would like to change about myself.
23. I often show affection toward my friends.
24. I often act upon suggestions made by coworkers.
25. My family only gets together for funerals or weddings.
26. I have difficulties relaxing and forgetting my worries even while on vacation.
27. Where I live the streets are well kept.
28. I frequently find it difficult to tell how my partner is feeling about something.
29. I have season's tickets to the theater, or symphony etc.
30. I am relaxed most of the time.

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31. I avoid talking to my child(ren) when I am displeased with them.
32. I usually find out about current events from other people.
33. My supervisor usually explains what has to be done clearly.
34. I frequently read books or articles about sports, and sports personalities.
35. In general, my surroundings are free from pollution.
36. My job allows me to be creative.
37. I usually know how my child(ren) are feeling without asking.
38. I make sure that I am aware of the political issues and the candidates' views on the issues before I vote.
39. I try to go places where I can meet new people.
40. Planning my vacation is often as enjoyable as taking it.
41. My partner and I have no difficulty discussing our sexual relationship.
42. I make donations regularly to charitable organizations.
43. There is poor cooperation between the various groups at work (e.g. departments)
44. I often spank my child(ren) for bad behavior.
45. My vote has no real effect on the outcome of elections.
46. I can usually laugh at myself.
47. I have difficulty starting conversations with other people.
48. I usually have better things to do with my time than play sports.
49. Although I like watching others perform, I would never do it myself.
50. I learn many things from my child(ren).
51. I only phone my relatives when I have to.

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52. I have difficulty finding time to keep in touch with my friends.

53. My vacations are usually very relaxing.

54. My partner and I have a good sexual relationship.

55. In the past year, I did not canvas for an organization which helps others.

56. My training is just right for the work I do.

57. Most people would say that I am a creative person.

58. I make clear rules for my child(ren) to follow.

59. I often encourage other people to vote.

60. At work I usually get a good reaction when I do well.

61. Most of the time I prefer to be alone rather than with friends.

62. My partner and I often work together to help each other meet goals.

63. Compared to most people my working hours are inconvenient.

64. I wear seat belts whenever I am in a car.

65. I frequently help my relatives.

66. I usually tell my friends what I think they want to hear.

67. I often spend my spare time working to make more money (e.g. weekends, vacation, etc.).

68. Because food prices are too high, I cannot buy all the foods I should have.

69. I usually wake up refreshed after a night's sleep.

70. I rarely help my child(ren) with their school work.

71. My opinions are rarely considered when decisions are made at work.

72. My friends and I enjoy making plans together.

73. I am an active member of a sports group or club.

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74. When I am doing something I often forget to take safety precautions.

75. I usually stay calm when my child(ren) misbehave.

76. At work, my supervisor would stand up for me, if it was necessary.

77. I learn a lot from my friends.

78. I rarely get away on my vacation because of the expense involved.

79. I rarely get caught in heavy traffic.

80. I would never donate my body to science.

81. Whenever I can, I use the stairs instead of the elevator.

82. My supervisor often asks me what I think about something.

83. I often find myself in situations where I just don't know what to do.

84. The age difference between my grandparents and I makes it difficult to communicate.

85. At work I have good employee benefits (e.g. pension plans etc.).

86. I keep in touch with my friends who have moved away.

87. I prefer to watch accidents at a distance because I don't want to get involved.

88. I have just enough variety in my job.

89. I have trouble living up to my own expectations.

90. Considering my ability and qualifications my pay is adequate.

91. People often come to me for help.

92. At work I have to do the same thing day after day.

93. I spend several hours each week on my hobby(ies).

94. Most of the time I can depend upon my relatives to help me when I need it.

95. Although I enjoy watching sports events, I rarely participate in them myself.

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96. Quite often I must do without the things I want because I lack the money.

97. I do volunteer work regularly.

98. My superiors at work are unapproachable.

99. I have goals that I hope to reach in the future.

100. I am usually uncomfortable at family get togethers.

101. If an other job opportunity came along, I would leave my job immediately.

102. On vacation, I often end up doing a few interesting things that I had not planned.

103. It is useless to give money to charity because very little of it ever gets to the people who need it.

104. I find myself smoking much more than I should.

105. I encourage my child(ren) to share their thoughts, and feelings with me.

106. My supervisor seems to be able to handle most problems that arise efficiently.

107. I seldom lose my temper.

108. I seldom have time to visit my relatives.

109. My friends often take advantage of me.

110. I only take part in sports for the exercise.

111. My partner does not try to change me.

112. I have to work overtime several times a week.

113. Sometimes I don't bother to discipline my child(ren).

114. Involvement in politics would be a waste of my time.

115. I have a feeling that some of my friends talk about me behind my back.

116. Often my partner and I have disagreements that are not solved.

pr

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117. **The number of people I work with is just right for me.**

118. **My supervisor rarely lets me know that he/she is pleased with my work.**

119. **I often have difficulty making up my mind about things.**

120. **I often plan trips just to visit my relatives.**

121. **I have to stay with my present job because there are no other jobs available.**

122. **I know the rules of at least three sports.**

123. **Friends have commented on how nice my home is.**

124. **I have trouble talking to my partner about a lot of things.**

125. **Several times each year I go to live productions (e.g. theater, symphony, concerts).**

126. **People usually have to urge me to go to a doctor when I am sick.**

127. **I do not go to political meetings.**

128. **I live in a quiet neighborhood.**

129. **I usually read the entertainment section of the newspaper.**

130. **When I visit my relatives we rarely talk about anything really meaningful.**

131. **There is a good possibility that I will be promoted in my job.**

132. **During the year I engage in several sport activities (e.g. golf, skiing, squash, etc.)**

133. **My partner and I find it easy to say how we feel about each other.**

134. **I get angry when people come to my door asking for donations.**

135. **I learn as much as I can about the issues in an election before I vote.**

136. **If I had a choice I would rather work for a different supervisor.**

137. **My work is meaningful to me.**

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138. I save some money each month for my vacation.

139. I belong to an organization that helps others.

140. My relatives know me quite well.

141. Promotions seldom occur where I work.

142. I often get very upset when I lose a game.

143. As often as I can I donate blood.

144. If my health were better I would do a lot more things.

145. I keep up on what government is doing.

146. I find it hard to criticize the people who work for me.

147. If I had an emotional problem, I'd rather discuss it with a friend than a relative.

148. I am given little chance to get ahead at work.

149. I try to do different things and go to different places on each vacation.

150. My child(ren) know what I expect from them.

151. I have worked in the campaign of a political candidate during an election.

152. I am not afraid to say what I think.

153. I am active in my union or professional group.

154. I rarely attend a sports event.

155. I would rather live in a less crowded neighborhood.

156. I have never done any volunteer work.

157. I have never done any writing (i.e. book, poetry, short stories).

158. I have regular dental checkups.

159. I often yell at my child(ren) when they are misbehaving.

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160. I'm too busy with other things to get involved in politics.

161. I try to keep in touch with my relatives even though some live far away.

162. Where I work, I receive training from time to time to improve my qualifications.

163. I have a hard time fitting holidays into my busy schedule.

164. I take more responsibility in our relationship than my partner.

165. I frequently get a chance to use all my skills at work.

166. I rarely buy artwork for my home (e.g. pictures, pottery, etc.)

167. I always feel hurt when someone criticizes me.

168. I feel free to talk to my relatives about my problems.

169. I engage in sports activity (e.g. golf, tennis, swimming) at least once a week.

170. I general I handle my money well.

171. I try not to bother my partner with my feelings.

172. My company has many policies that seem to make no sense.

173. I have been to an art gallery or museum several times in the part year.

174. When programs about politics come on the television or radio, I usually turn to another program.

175. I put myself down too much.

176. I often go for months without contact with my relatives.

177. I make friends easily.

178. My partner and I never take a vacation by ourselves.

179. I have enough clothes for most occasions.

180. I regularly help support at least one charitable organization.

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181. I only go to the dentist when my teeth bother me.

182. I frequently leave my child(ren) with a babysitter.

183. I believe that the government will never be able to solve the country's problems.

184. If I realize that some goals I have set for myself are too high, I change them.

185. I am achieving something important through my work.

186. I am involved in noncompetitive sports (e.g. swimming, running, skiing, etc.).

187. Given my income my housing is costing too much.

188. The government spends too much money supporting the arts.

189. I'm never exactly sure what my supervisor expects of me.

190. I often feel envious of other people.

191. At work my ideas are seldom considered.

192. I make sure that I take a holiday at least once a year.

QUALITY OF WELL-BEING SCALE

The Quality of Well-Being Scale is an interviewer-administered instrument that measures well-being in individuals based on the social preferences that society generally associates with a person's level of functioning at specific point in time. For each individual the scale averages values across three ratings of functioning: mobility, physical activity, social activity, and across one rating of symptomatic complaints that might inhibit function. Based upon the interview, a single functional level is assigned to each respondent within each of the four domains, and each level is given a weight based on large population surveys of preferences of each functional level.

Abbreviated Name: QWB
Author(s): John Anderson, Robert M. Kaplan
Purpose: To measure health-related quality of life, to monitor the health of populations over time, or to evaluate the efficacy and effectiveness of clinical therapies or practices.
Population: Adult
Age Range : 18 to 120 years
Type of Instrument: Utility / Quality of life
Mode of Administration:

Rater:	Interviewer-administered
Time required:	15-30 minutes
Response Options:	Yes/no - 4-point Likert scale - endorse last 6 days
Scoring:	Global score
Score Direction:	Higher scores show better QoL
Weighting:	Yes

Number of Items: 31
Original Language: English
Existing Translations : Chinese, French, German (modified version), Hmong, Japanese, Khmer (Cambodian), Laotian, Navajo, Spanish, Vietnamese

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Contact for information and permission to use:

Robert M. Kaplan
c/o Kristin David
UCSD Health Outcomes Assessment Program
9500 Gilman Dr.
La Jolla, CA, 92093, USA
Phone: 858-622-1771
Fax: 858-622-1290
E-mail: kdavid@ucsd.edu

Dimensions covered by the questionnaire :

- Symptoms
- Mobility

- Physical activities
- Social activities

Key References:

1. Kaplan R et al. The Quality of Well-Being Scale: Rationale for a Single Quality of Life Index. In: Quality of Life Assessment: Key Issues in the 1990s. Walker, Stuart R.; Rosser, Rachel M. (editors). Dordrecht, The Netherlands: Kluwer Academic Publishers 1993:65-94
2. Kaplan RB, Atkins CJ, Timms R. Validity of a quality of well-being scale as an outcome measure in chronic obstructive pulmonary disease. Journal of Chronic Diseases 1984;37(2):85-95

This paper evaluates the validity of the Quality of Well-being Scale (QWB) as an outcome measure for research on Chronic Obstructive Pulmonary Disease (COPD). The Quality of Well-being Scale was originally designed for use as a general health outcome measure. One criticism of this approach has been that it may not be valid in studies limited to a specific disease or condition. We report correlations between the QWB and a variety of other outcome measures obtained in an experimental trial evaluating the benefits of behavioral programs for COPD patients. The data from the trial suggest that the QWB is substantially correlated with both performance and physiological variables relevant to the health status of COPD patients. An advantage of the QWB is that it can be transformed into well-year units for cost-effectiveness studies. It is concluded that the QWB has many advantages as an outcome measure for specific disease groups.

QUALITY OF WELL-BEING – INTERVIEWER ADMINISTERED

A. For each of the following symptoms or problems determine if the patient experienced this problem **yesterday**.

"I'm going to ask you about a few symptoms you may have experienced in the past **day**." (Check all that apply)

"Did you have this symptom or problem **yesterday**?"

1. Loss of consciousness
___ Yes
___ No

2. Trouble remembering or thinking clearly
___ Yes
___ No

3. Pain in the stomach
___ Yes
___ No

4. Pain or other discomfort in the chest
___ Yes
___ No

5. Groin pain, bleeding, itching or abdominal discharge
___ Yes
___ No

6. Pain in your joints, like your neck, back, arms or legs
___ Yes
___ No

If any symptoms or problems were endorsed in this section, skip to Section C.

B. If **none** of the symptoms were experienced in Section A. determine if the patient experienced any of the following problems in the **past** day. Continue down the list until a problem is identified (if any). Once a problem is identified, skip to Section C.

"Did you have this symptom or problem **yesterday**?"

1. Difficulty with bowel movements or any pain or discomfort in the rectal area
___ Yes
___ No

2. Difficulty urinating
___ Yes
___ No

3. Upset stomach, vomiting or diarrhea
___ Yes
___ No

4. General tiredness, weakness, or weight loss
___ Yes
___ No

5. Cough, wheezing, or shortness of breath
___ Yes
___ No

6. Spells of feeling upset, depressed or crying
___ Yes
___ No

7. Headache
___ Yes
___ No

8. Dizziness, or ringing in ears
___ Yes
___ No

9. Spells of feeling hot, nervous, or shaky
___ Yes
___ No

10. Burning or itching rash on large areas of the body
___ Yes
___ No

11. Trouble talking (e.g. lisp, stuttering, hoarseness, or being unable to speak)
___ Yes
___ No

12. Any trouble seeing with or without glasses or contact lenses
___ Yes
___ No

13. Burning itching or pain in one or both eyes
___ Yes
___ No

14. A problem with being overweight or underweight
___ Yes
___ No

15. Any very noticeable skin imperfections, many warts or large scars
___ Yes
___ No

16. Trouble hearing with or without a hearing aid
___ Yes
___ No

17. A stuffy or runny nose
___ Yes
___ No

18. A sore throat
___ Yes
___ No

19. An earache
___ Yes
___ No

20. A toothache
___ Yes
___ No

21. Sore lips, tongue, or gums
___ Yes
___ No

22. A problem with missing or crooked teeth
___ Yes
___ No

23. Were you supposed to take prescribed medication or follow a prescribed diet for health reasons (This asks if one or both were **prescribed**, not what the patient did.)
___ Yes
___ No

24. Wore glasses or contact lenses
___ Yes
___ No

25. A problem with breathing smog or unpleasant air
___ Yes
___ No

26. Any other symptoms, health complaints, or pains that have not been mentioned? (Describe:_____)
___ Yes
___ No

C. MOBILITY

1. Did you drive or ride in a car yesterday?
___ Yes

If yes: Did you use help from another person in order to drive a car yesterday? If so, why?

___ Yes, health related
___ Yes, not health related
___ No
___ No

If no: Were the reasons you did not drive yesterday related in any way to your health?
___ Yes
___ No

2. Did you use any public transportation yesterday?

___ Yes

If yes: Did you use help from another person to use public transportation yesterday? If so, why?

___ Yes, health related
___ Yes, not health related
___ No
___ No

If no: Were the reasons you did not use public transportation yesterday related in any way to your health?
___ Yes
___ No

If no: If you HAD used public transportation yesterday, would you have used help from another person? If so, why?
___ Yes, health related
___ Yes, not health related
___ No

D. PHYSICAL ACTIVITY: your level of physical activity **yesterday**

1. Did you spend more than half of yesterday in a wheelchair?
___ Yes

If yes: Did you move or control the movement of the wheelchair without help most of the time yesterday?
___ Yes
___ No. Skip to Section E.
___ No

2. Did you spend more than half of yesterday in bed? If so, why?
___ Yes, health related. Skip to Section E.
___ Yes, not health related. Skip to Section E.
___ No

4. Did you spend more than half of yesterday in a chair?
If so why?
___ Yes, health related
___ Yes, not health related
___ No

5. Did you limp or use a cane, crutch or walker yesterday?
___ Yes
___ No

E. SOCIAL ACTIVITIES:

1. Did you use help from another person with your personal care needs? (such as eating, bathing, dressing, or getting around your home.) If so, why?
___ Yes, health related
___ Yes, not health related
___ No

2. Did you use help from another person in handling your routine needs? (such as everyday chores, doing necessary business, shopping, or getting around for other purposes).
___ Yes, health related
___ Yes, not health related
___ No

3. Did you do any household activities? (such as working in or around the house or yard, caring for children, cooking, or cleaning)
___ Yes

If yes: Were you limited in any way in the amount or kind of household activities you did? (such as not doing certain tasks or strenuous work, or taking special rest periods or working only part of the day)
___ Yes
___ No
___ No

If no: Was the reason you did not do any household activities related in any way to your health?
___ Yes
___ No

If no: If you HAD done household activities, would you have been limited in any way in the amount or kind of work done? (such as not doing certain tasks or strenuous work, or taking special rest periods)
___ Yes, health related
___ Yes, not health related
___ No

4. Were you limited in any activities other than household activities, such as hobbies, shopping, recreational, social, or religious activities? If so, why?
___ Yes, health related
___ Yes, not health related
___ No

QUALITY OF WELL-BEING SCALE – SELF-ADMINISTERED

The Quality of Well-Being scale (QWB) is relatively long and complex; it has some branching and probe questions and requires a trained interviewer. UCSD Health Outcomes Assessment Program therefore developed a self-administered QWB; referred to as the Quality of Well-Being scale, Self-Administered (QWB-SA) that addresses some of these issues. There are several strengths of the QWB-SA: (1) Includes assessment of symptoms in addition to various areas of functioning; (2) The expanded list of symptoms now includes additional mental health items; (3) To reduce recall bias, the QWB-SA assesses only the 3 days prior to completion of the questionnaire; (4) The scoring of the instrument utilizes population-derived preference weights.

Use of the QWB-SA is growing rapidly. The UCSD Health Outcomes Assessment Program is conducting a strong and diverse research program toward establishing the psychometric properties of this measure. Current studies are addressing the ability of the QWB-SA to detect changes in samples of migraineurs, cataract surgery patients, mental health populations, arthritis patients, as well as validating the sensitivity of this measure translated in Spanish, German, Italian, Swedish, French, and Dutch.

Abbreviated Name: QWB-SA
Author(s): Robert M Kaplan, Theodore G Ganiats and William J Sieber
Purpose: To develop a clinically relevant, preference-weighted, self-administered version of the QWB.
Population: Adult
Age Range : 18 to 120 years
Type of Instrument: Utility/Quality of Life
Mode of Administration: Self - administered

Rater:	Self-administered
Time required:	10-15 minutes
Response Options:	Yes/no - Day symtoms or dysfunction was experienced
Scoring:	Global score: Minimum score: 0 / Maximum score: 100
Score Direction:	Higher scores show better QoL
Weighting:	Yes

Number of Items: 78
Original Language: English
Existing Translations : Dutch, French, German, Italian, Spanish, Swedish

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Contact for information and permission to use:

Erik J. Groessl, Ph.D.
University of California, San Diego (UCSD)
Health Outcomes Assessment Program
9500 Gilman Drive, Mail Code 0994
La Jolla, CA 92093-0994, USA
Phone: (858) 622-1789
Fax: (858) 622-1790
Email: egroessl@ucsd.edu

Key References:

1. Kaplan RM, Sieber WJ, Ganiats TG. Comparison of Quality of Well Being scale with a self-administered questionnaire. Psychology Health 1997 ;12 :783-791
2. Sieber WJ, David KM, Adams JE, Kaplan RM, Ganiats TG. Assessing the impact of migraine on health-related quality of life: An additional use of the quality of well-being scale-self-administered. Headache 2000 ;40(8):662-71.

Objectives: To compare the interviewer-administered Quality of Well-being Scale (QWB) with a self-administered form (QWB-SA) for patients with migraine, and to compare the health status of migraineurs to other medical populations. Background: With the increasing need to document the cost-effectiveness of treatment for migraine, limitations with both the Medical Outcomes Study Short Form-36 items and the QWB have been an impediment to research using cost-effectiveness as an outcome. Demonstrating the sensitivity of an alternative instrument which addresses these limitations would facilitate cost-effectiveness analyses on treatments for migraine. Methods: Eighty-nine adults (87% women) known to suffer from migraine were asked to complete both the interviewer-administered QWB and the self-administered version (QWB-SA) on three occasions. The first occasion was on a day when no migraine was experienced in the previous 7 days. The second and third assessments were completed within 48 hours of the onset of a migraine. Results: While both the QWB and the QWB-SA successfully distinguished migraine from nonmigraine days, more migraines were reported on the QWB-SA. Overall, both instruments showed similar patterns of patient dysfunction during a migraine attack. Each component of the QWB-SA successfully distinguished migraine from nonmigraine days, and the QWB-SA showed a linear sensitivity to pain intensity and disability during a migraine episode. Both instruments are able to detect a migraine's effect on multiple domains of quality of life. Study participants scored significantly lower on the QWB-SA during a migraine episode than several comparison medical populations. Conclusions: The QWB and the QWB-SA appear to have sensitivity to migraine severity, and the ability to quantitate an effect in multiple quality-of-life domains. Both measures can be used to calculate quality-adjusted life-years, thus facilitating cost-effectiveness and health policy work in this important clinical area.

3. Andresen EM, Rothenberg BM, Kaplan RM. Performance of a self-administered mailed version of the Quality of Well-Being (QWB-SA) questionnaire among older adults. Med Care 1998;36:1349-1360

Objectives: The Quality of Well-Being questionnaire is a measure of health-related quality of life (HRQoL) that has several desirable properties. Its widespread use has been hindered because it is difficult to administer. To overcome this limitation, a new self-administered form has recently been developed. This study examined the feasibility of using the Quality of Well-Being-Self-Administered (QWB-SA) questionnaire in an older population. Methods: The Quality of Well-Being-Self-Administered questionnaire was sent to 430 community-dwelling individuals aged 65 years and older who were randomly selected from primary care physicians' offices. Response patterns, scaling distributions, and the acceptability of the survey were examined for all respondents. The results of the QWB-SA questionnaire were compared to the Sickness Impact Profile (SIP) and the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36) for those individuals who also had completed the latter two surveys approximately 10 months earlier and whose health had not changed substantially in the meantime. Results: Three hundred and one older adults (70%) responded. The mean QWB-SA questionnaire score was 0.7035. The scores were not skewed, and there were no floor or ceiling effects. The mean time to complete the QWB-SA questionnaire was 14.2 minutes, which was significantly shorter than for the SIP (19.3 minutes) but significantly longer than for the SF-36 (12.5 minutes). Subjects rated their satisfaction with the QWB-SA questionnaire somewhat lower than for the SIP and similar to SF-36. Correlations between the QWB-SA questionnaire and the SIP and SF-36 were moderate and were generally stronger for measures of physical health than for other domains such as mental health. Conclusions: The self-administered QWB questionnaire was acceptable to older respondents, and it correlated with other measures of health-related quality of life. It can be considered as a candidate for some research applications among older adults.

Quality of Well-Being Self-Administered (QWB-SA) Scale User's Manual

William J. Sieber, Ph.D. Erik J. Groessl, Ph.D. Kristin M. David, MPH Theodore G. Ganiats, M.D. Robert M. Kaplan, Ph.D.

Health Outcomes Assessment Program
University of California, San Diego

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Introduction

Measuring health outcomes has become an important objective for health care professionals in research, clinical care, health care finance, and public policy. One of the main purposes of measuring health outcomes is to document levels of patients' health status and changes in health status over time. Depending on the need of the assessor, health status can be measured in many ways. It can be assessed by using endpoints of mortality or disease diagnosis, or by using intermediate outcomes such as blood pressure, cholesterol, or Body Mass Index. Intermediate outcomes are often easier to measure and do not rely upon patient self-report, but may not directly affect health care consumers. Outcomes can be disease-specific or generic, or one can attempt to measure outcomes such as symptoms, function, and mortality, which more directly affect the quality of life of health care consumers.

Another issue in the assessment of health is whether to use a disease-specific instrument or a more comprehensive measure of health-related quality of life (HRQoL). Disease-specific measures are often perceived as being more sensitive to subtle changes in the disease of interest, but may miss changes in other areas of health or functioning. Given the unpredictable impact interventions can have on multiple body systems, it is essential to assess health in ways that can capture a patient's overall functioning and well-being.

Health-related quality of life (HRQoL) is a concept used to describe a comprehensive picture of how a person's health affects their overall well-being. The metric that has become a standard measure of HRQOL in medical cost-effectiveness research is the Quality Adjusted Life Year (QALY) (Gold et al., 1996). QALYs integrate HRQoL with the duration of life to provide a single comprehensive expression of health outcome. The Quality of Well-Being (QWB) scale was developed in the 1970's as a comprehensive measure of health-related quality of life (Kaplan, Bush, & Berry, 1975). The QWB is one of the few instruments that can help calculate QALYs as an expression of health outcome. It has been extensively validated and its psychometric properties are well established (Kaplan, Anderson, and Ganiats, 1993). However, the widespread use of this instrument has been low in part due to the length and difficulty in its administration. Thus, the Quality of Well-Being Scale-Self Administered (QWB-SA) was created (Kaplan, Ganiats, and Sieber, 1996). The QWB-SA was developed in response to previously identified limitations of the QWB, and is easier to administer in most research and clinical assessment protocols than the interviewer-administered QWB.

This manual is designed to serve as a guide to the administration, scoring, and interpretation of the QWB-SA. Psychometric properties are reported and validation studies are described. In addition, data from studies that have used the QWB-SA are provided to assist the user of the QWB-SA in interpreting scores. References are also provided.

The General Health Policy Model and the Quality of Well-Being Scale (QWB)

The assessment of health-related quality of life has developed significantly since the 1970's. Among the instruments that assess overall HRQOL, only a few can be used for cost-utility analysis. Cost-utility analysis is defined as cost-effectiveness analysis (CEA) that uses QALYs as the outcome. QALYs have been identified as the preferred outcome metric by Gold et al. (1996) in hopes of standardizing CEAs in medicine and healthcare. As mentioned above, QALYs incorporate both quality of life and mortality into one score which allows for comparisons across diseases and populations. In the past, CEAs have used a variety of outcomes, thus often making comparisons difficult. Standardization of outcomes, definitions, and methods of CEA is an important step for integrating findings.

The Quality of Well-being (QWB) scale was the first instrument specifically designed to measure quality of life for the estimation of QALYs. The QWB is a preference-weighted measure combining three scales of functioning with a measure of symptoms and problems to produce a point-in-time expression of well-being that runs from 0 (for death) to 1.0 (for asymptomatic full function). Most HRQoL measures focus on functioning; the QWB and QWBSA have a functioning component complemented by a strong symptom component. Prior work by our group demonstrated that on any particular day, nearly 80% of the general population is optimally functional. However, fewer than half of the population experience no symptoms. Symptoms or problems may be severe, such as serious joint pain, or minor such as taking medication or following a prescribed diet for health reasons.

The QWB was developed using theory from the General Health Policy Model (Kaplan, 1993b, 1993c; Kaplan & Anderson, 1996; Kaplan, Anderson & Ganiats, 1993). This model includes several components, including mortality (death) and morbidity (health-related quality of life). In several papers, Kaplan and colleagues have suggested that diseases and disabilities are important for two reasons: first, illness may cause life expectancy to be shortened, and second, illness may make life less desirable at times prior to death. Thus in assessing the impact of a health intervention, one must measure both a possible decrease in mortality as well as an improvement in health. In addition to mortality and morbidity, the General Health Policy Model incorporates preference for observed health states (utility) and duration of stay in health states (prognosis).

Utility studies looking at how people value health have been conducted to place the observable states of health and functioning onto a preference continuum for the desirability of various conditions, giving a "quality" rating between 0 for death and 1.0 for completely well. A Quality-Adjusted Life Year (QALY) is defined as the equivalent of a completely well year of life, or a year of life free of any symptoms, problems, or health-related disabilities. Consider, for example, a person who has a set of symptoms and is in a state of functioning that is rated by community peers as 0.5 on a 0.0 to 1.0 scale. If the person remains in that state for one year, he or she would have lost the equivalent of 1/2 of one year of life. Thus, a person limited in activities who requires a cane or walker to get around the community would be hypothetically rated at 0.50. If he or she remained in that state for an entire year, the individual would lose the equivalent of one-half year of life. However, a person who has the flu may also be rated as 0.50. In this case, the illness might only last three days and the total loss in QALYs might be 3/365 X 0.50 which is equal to 0.004 QALYs. This may not appear as significant an outcome as the more disabled person. But suppose that 5,000 people in a community get the flu. The well years lost would then be 5,000 x .004 which is equal to 20 years of perfect health in one person. The quality-adjusted life expectancy is the current life expectancy adjusted for diminished quality of life associated with dysfunctional states and the duration of stay in each state.

By administering the QWB before and after a treatment or intervention program, the intervention can be described in terms of the quality adjusted life years that it produces or saves. When costs are examined (using standardized methods), every intervention can be given a cost/QALY value. This value delineates how much it costs, on average, to produce an extra QALY for each subject in a given study.

Several studies have demonstrated that the QWB is responsive to clinical change in a variety of patient populations. For example, QWB scores have been shown to be associated with health improvements in patients with cystic fibrosis (Orenstein, et al., 1989), chronic sinusitis (Hodgkin, 1994), and cochlear implant (Harris, et al., 1995). In addition, the QWB is responsive to medications expected to have a minor effect, such as oral gold treatment for patients with arthritis (Bombardier, et al., 1986) or medications that have a larger effect, such as AZT for patients with HIV infection (Kaplan, Anderson, Wu, et al., 1989). Other applications of the QWB include chronic obstructive pulmonary disease (Kaplan, et al., 1984), AIDS (Kaplan, et al., 1989), diabetes mellitus (Kaplan, et al., 1987), atrial fibrillation (Ganiats, et al., 1992), lung transplantation (Squier, et al., 1994), cancer (Kaplan, 1993a), depression (Kaplan, 1997), schizophrenia (Patterson, et al., 1996), fibromyalgia (Kaplan, Schmidt, and Cronan, 2000), osteoarthritis (Groessl, Kaplan, and Cronan, 2000), and several other conditions (Kaplan, 1993b). Further, the method has been used for health resource allocation modeling and served as the basis for the innovative experiment on rationing of health care by the state of Oregon (Kaplan 1993b, 1993c).

The Quality of Well-Being Self-Administered (QWB-SA) Scale

A. Development of the questionnaire

One of the major criticisms of the QWB is that it is more expensive and difficult to administer than most other generic measures. The QWB questionnaire is long and complex, employing branching and probing questions, thus requiring a trained interviewer. The demand for rapid health status assessment is exemplified by the current widespread use of the SF-36, though the SF-36 cannot be used to produce QALYs. What is needed is a clinically useful, self-administered instrument that is sensitive to changes at the higher levels of functioning, and that produces QALYs for important cost-effectiveness analyses. A self-administered version of the QWB, known as the QWB-SA, was developed to meet this need.

There are several improvements seen in the QWB-SA. First, several items assessing mental health are now included. Second, the assessment of symptoms follows a clinically useful Review of Systems model, rather than clustering symptoms based on preference weights. Third, additional symptoms not included in the interview format of the QWB are in the symptom assessment portion of the QWB-SA. And fourth, the administration of the questionnaire no longer requires a trained interviewer and can be completed in less than 10 minutes.

The period assessed by the QWB-SA is shorter than in the QWB. The QWB asked patients about symptoms and function “over the past 6 days” prior to the day of administration, whereas the QWB-SA questions refer to the 3 days prior to the day of administration. This change was designed to reduce respondents’ recall bias without decreasing the instrument’s ability to assess over a period of time. Assessing 3 days rather than 6 days also results in a more rapid administration. The impact on the overall quality of life score of using only the last 3 days was examined by dropping information from Day 4, 5,

6 and recalculating QWB scores based only on the past 3 days. No significant differences in scores were found.

The development of the QWB-SA has gone through several stages. First, a list of symptoms and health-related problems was developed. The current version of the interviewer-administered QWB uses a list of 26 symptom clusters; these clusters are based on the preference weights assigned to each symptom. Despite having similar preference weights, some of the symptoms within a given group were clinically heterogeneous or unrelated. Therefore, the endorsement of a symptom cluster did not specifically identify the health problem experienced; the endorsement of an item on the QWB-SA does suggest symptoms that are clinically related.

In addition to limitations related to the groupings of the symptoms on the QWB, the symptom list did not adequately assess psychological symptoms. There were a number of clusters that addressed some of the common symptoms of anxiety and depression, but more were needed as these problems are often expressed in different ways. Thus, the symptom checklist of the QWB-SA was expanded to 58 symptom complexes including at least 12 symptoms that are typically considered "psychological." Most items focus on one problem related to one body system.

The expansion of the symptom checklist for the QWB-SA involved conducting several focus groups comprised of physicians. Input on which symptoms would be important to be aware of led to structuring symptoms along a medical Review of Systems. The different symptoms selected thus reflect different important aspects of health, are understood by physicians as distinct signs/predictors of various disease conditions, and cover different degrees of severity. A total of 58 different symptoms emerged. The assessment of symptoms in the QWB-SA reflects a broad array of symptoms, and has been organized to closely resemble how a clinician might conduct an assessment of a patient's symptoms, again potentially increasing the clinical utility of the QWB-SA.

The format for the QWB-SA includes five sections. The first part assesses the presence/absence of 19 chronic symptoms or problems (e.g., blindness, speech problems). The question format does not assess each of the previous 3 days (as in the rest of the questionnaire) with the expectation is that these chronic conditions do not vary much over the 3-day assessment period. These chronic symptoms are followed by 25 acute (or more transient) physical symptoms (e.g. headache, coughing, pain), and 14 mental health symptoms and behaviors (e.g., sadness, anxiety, irritation). The remaining sections of the QWB-SA are similar to the QWB and include assessment of a person's mobility (including use of transportation), physical activity (e.g., walking and bending over), and social activity including completion of role expectations (e.g., work, school, or home).

B. Derivation of preference weights

A unique aspect of the QWB-SA is that a person's score reflects a societal perspective on the value of that person's level of functioning and well-being. Preference weights (i.e., societal value of various health states) used with the QWB-SA were derived from a community sample. Preference weights have been found to be quite consistent across groups (Balaban, et al., 1986; EuroQol Group, 1990; Froberg and Kane, 1989c). While the community sample used for the development of the QWB-SA preference weights was geographically homogeneous, the age and gender distributions were similar to the census statistics for the U.S. population in 1990.

A total of 435 English-speaking adults were drawn from several primary care clinics as well as two college campuses in San Diego. The final sample included 239 females (56%) and 191 males between the ages of 18 and 85 (mean age = 38 years). Distribution by age, gender, and ethnicity approximated those reported in the 1990 U.S. census.

Each item included on the QWB-SA was described as a health state to be rated on a 0 to 100 scale. Subjects were asked to use "0" as an anchor for death/worst possible health state and "100" for optimum health (no dysfunction or symptoms). Subjects were provided two examples to assess their understanding of the task: one that described the maximum dysfunction in the areas of mobility, physical activity, social role activity, while the other example listed no dysfunction or symptoms. Due to the very large number of items to be rated and the burden created by having each subject rate each possible health state, each subject completed a randomly selected subsample of 12 items. Ratings for QWB-SA items included one symptom and a level of impairment for a mobility, physical activity, or social activity item. Subjects rated each symptom separately and in combination with multiple levels of one of the functional scales (i.e., mobility, physical activity, social activity). Once all subjects provided ratings, preference weights were estimated using an adaptation of Multiattribute Utility Scaling method (Anderson and Zelinski, 1990). The method assumes an additive model, such that an item's weight is calculated with the following formula:

item weight = 1.0 – (mean rating/100)

Once preference weights were calculated for all symptom items, weights for mobility, physical activity, and social activity were calculated by subtraction. That is, once the weight for a symptom (i.e., shortness of breath) was established, the mean rating for a health state with both a symptom and a functional item (e.g., confined to bed) was subtracted from the symptom alone to determine the preference weight assigned each item from the functional scale. In this manner, new preference weights were derived for the QWB-SA and are presented in Appendix A. Item preference weights are higher on the QWB-SA than weights originally calculated for the QWB more than 20 years ago (Kaplan, et al., 1978). Thus, the lowest total score for a living subject on the QWB-SA is .09, whereas for the QWB, it is .33. This results in a greater distribution of scores that approaches a normal curve as compared to the truncated distribution evident with the QWB. Current research is documenting the distribution of QWB-SA scores approaches normality to a greater degree than the HUI and EuroQoL and has fewer ceiling effects (Ganiats, Barrett-Connor, Sieber, 1999 Barcelona ISQoL)

Psychometric Properties of the QWB-SA

The initial published report of the psychometric properties of the QWB-SA included a test of the impact of mode of administration on overall scores as well as test-retest reliability (Kaplan, Sieber, and Ganiats, 1997). *Using the same preferences weights in the scoring algorithm for both the interviewer-administered QWB and the QWB-SA*, a 2 x 2(Mode x Time) factorial design allowed for two types of comparison: to detect differences between the two modes of administration using the same scoring algorithm, and to assess the stability of scores on each instrument over a 4 week time period. Each of 218 English-speaking adults recruited from primary care clinics were assigned to one of four groups that differed in mode of administration at each time point: 1) interviewer-interviewer, 2) interviewer-SA, 3) SA-SA and 4) SA-interviewer. As Table 1 suggests, the two measures yielded nearly identical scores at both the baseline and the one-month evaluations (with all main effects and interactions in the model being non-significant), implying that the different modes of administration produce equivalent results. These results also demonstrated that both the QWB and QWB-SA scores remain stable over a one-month time period for relatively healthy adults not under-going any health intervention or change: r = .60 for the QWB, and r = .77 for the QWB-SA.

Table 1. Means and Standard Deviations for QWB by Mode of Administration

Mode	Baseline	1 Month
QWB	.708 (.119)	.707 (.108)
QWB-SA	.701 (.101)	.700 (.110)

The same analysis was then performed on the QWB-SA using the new preference weights derived specifically for the QWB-SA. (*Note: All QWB-SA scores reported in this manual hereafter reflect the use of the preference weights to be used in future administrations of the QWB-SA.)* The same data from respondents reported in Kaplan, Sieber, and Ganiats, (1997) was used, though the QWB-SA total scores were calculated using the newly constructed preference weights (Appendix A). A total of 118 females (54%) and 100 males between the ages of 18 and 85 (mean age = 50 years) completed one of the two instruments at both time points.

First, data were analyzed by comparing both instruments' total scores at both the baseline and one-month evaluations (See Table 2). (Interviewer-administered QWB scores are presented in the following tables for comparison.) Test-retest correlations were computed for each instrument and showed greater temporal stability for the QWB-SA (r=.80) than for the QWB (.60; both p<001). Results did show that QWB-SA scores were significantly lower than the QWB scores at baseline ($F(1,217)=18.06$; $p<001$) and at one month follow-up ($F(1,217)=4.00$,
$p<05$).

Table 2. Means (and standard deviations) for QWB by Mode of Administration & Time

Mode	Baseline	1 Month
QWB	.709(.112)	.699 (.112)
QWB-SA	.634 (.159)	.663 (.149)

QWB-SA scores were compared between groups based on gender, ethnicity, and education. Substantial literature suggests that women live longer than men, yet report greater morbidity (Wingard, 1984). A sensitive health status measure should capture these differences in function and symptom reporting. Current results reflect such differences on the QWB-SA. Significant negative correlations were found between age and the QWB-SA (r= -.23) and QWB (r = -.20; both r's p<05). Given men in this sample were older (mean age 52.7) than the women (mean age was 45; $F(1, 217) = 22.4$, $p<001$), ANCOVAs performed to examine gender differences on each measure including age as a covariate. Table 3 shows the age-adjusted means for men and women on both instruments; no differences were found by

gender on the interviewer version of the QWB, though women did score lower than men on the QWB -SA ($F(1,217)= 13.96$, $p< 001$).

Table 3. Age-adjusted Means (Standard Error of Measurement) by instrument and gender

Mode	Males	Females	p <
QWB	.716 (.011)	.697 (.009)	ns
QWB-SA	.692 (.016)	.614 (.014)	.001

Finally, differences in scores between ethnic groups were also examined for each instrument. Given the low number of minority subjects who participated in this validation study, scores for all non-Hispanic Caucasians were compared to the mean for all other subjects combined. The age-and gender-adjusted means in Table 4 show no differences between these two groups on either the QWB or QWB-SA, though this analysis has limited power due to a small sample size.

Table 4. Age-adjusted means (Standard Error of Measurement) by instrument and ethnicity

Mode	Caucasian N = 169	Non-Caucasian N = 45	p <
QWB	.724 (.015)	.695 (.026)	ns
QWB-SA	.641 (.017)	.614 (.033)	ns

Similar analyses on QWB-SA scores showed no statistically significant differences by educational level (adjusted by age and gender; see Table 5). However, the limited sample size in this study may have limited the statistical power to detect differences seen in Tables 4 & 5. More research is clearly needed to understand the possible influence these socio-demographic variables have on QWB-SA scores.

Finally, each subject rated his/her overall health (i.e., 5-point scale from "poor" to "excellent") at the end of each administration of the QWB-SA. This rating was used as the independent variable in a one way ANOVA with linear contrasts, with QWB-SA scores serving as the dependent variable. Table 6 shows the significant linear trend that emerged ($F(1, 152)=62$; $p<.001$), thus providing convergent validity for overall QWB-SA score and self-rating of health status.

Table 5. Age-adjusted means (Standard Error of Measurement) by instrument and education

Education	n	QWB-SA total
HS graduate or less	17	.590 (.038)
some college	46	.661 (.021)
college degree	19	.635 (.033)
some graduate school or graduate degree	19	.638 (.035)

Table 6. QWB-SA and (SEM) score by self-rating of health

Self-rated health	n	QWB-SA total
Poor	11	.448 (.032)
Fair	32	.536 (.017)
Good	33	.639 (.020)
Very good	54	.696 (.025)
Excellent	23	.758 (.032)

Ongoing research has been demonstrating sensitivity of the QWB-SA to headache status in migraineurs (Sieber, David, Adams, Kaplan, and Ganiats, 2000), depression severity (Pyne, Sieber, David, Kaplan, Rapaport, and Williams, 2001), expected differences in a variety of medical conditions (Frosch, Sieber, Wiesman, Kaplan, 2000) and responsiveness to cataract surgery (Kaplan, Rosen, and Sieber , 2000). Additional studies that have reported on the use of the QWB-SA can be found in Appendix B.

It must be noted that the studies listed in Appendix B do not constitute a normative database. The studies were selected based on the overall quality of the study design, sample size, and generalizability of the study participants to other populations. There are many more research projects using the QWB-SA than are listed in Appendix B; the QWB-SA data reported is done in the hope that researchers can better estimate sample size for their study and to place their own participants' scores within a broader context.

Use of the QWB-SA

A. Modes of Administration

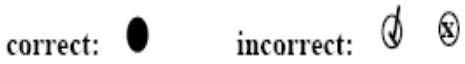
The QWB-SA is designed to be self-administered. The instructions below pertain to the scannable form used by UCSD and can be accessed by researchers for a nominal fee.

A.1 Self-Administered

Although the QWB-SA contains brief instructions at the top of the form, we highly recommend that researchers review the instructions with their participants. This facilitates accurate, consistent, and complete responses to the questions. Following are directions to investigators for instructing participants in self-administration of the QWB-SA.

General Instructions:

• The QWB-SA form (as designed, produced, and distributed by the UCSD Health Outcomes Assessment Program) can be completed using either a black or blue ball point pen; use of a #2 pencil is discouraged and use of felt tip ink pens are not permissible.
• Circles provided for a patient's response to any item on the QWB-SA should be filled in completely. Putting check marks or lines through the circles is not acceptable.
• The "Today's Date" field should be filled out "Month/Day/Year." For example, February 5, 2001 should be entered in the date field as "02/05/01."
• The "Participant" field (at the bottom of each side) should have the subject's identification number *left justified*.
• The "Protocol Number" field (at the bottom of the back side) is a free field that can be determined by the researcher or data manager. If the questionnaires are to be scanned at any point, entries in the "Protocol Number" field should be *left justified*.
• The "Investigator Number" field (at the bottom of the back side) allows for the opportunity of identifying the person collecting the data or the site from which data is being collected. Entry of such an identifier should be *left justified.*



Specific Instructions:

Questions 1a-1k are a list of chronic symptoms as well as commonly used health aids. For these questions the subject simply fills in the circle corresponding to "Y" (for yes) if s/he currently experiences the symptom or uses the health aid listed, or "N" (for no) if the subject is not currently experiencing the symptom or using the health aid listed.

For questions 2-8, the QWB-SA scale queries subjects on their functional health status, including the presence of certain physical symptoms (Q2) and mental health symptoms (Q3), the subject's ability to perform self-care activities (Q5), limitations in mobility (Q6), physical activity (Q7), or usual activities (Q8). These questions refer to a three-day time period that corresponds to the three days directly preceding the day the questionnaire is completed. For example, if a participant were completing the QWB-SA on Thursday, February 5, 2001, s/he would answer questions about Wednesday, 02/04/01 ("Yesterday" on the QWB-SA form), Tuesday, 02/03/01 ("2 Days ago"), and Monday, 02/02/01 ("3 Days

ago"). It is important that the subject understand the specific days s/he is being asked about. If the subject did not experience a particular symptom in the past 3 days, s/he would fill in the circle corresponding to "No Days." Symptoms are reported for each of the 3 days separately. For example, if the subject experienced the symptom 2 days ago but not yesterday or three days ago, s/he would fill in only the circle corresponding with 2 days ago; if the subject experienced the symptom on all of the past 3 days s/he would fill in a circles for each of the 3 days separately.

Question 4 asks if the subject had any symptoms that were not mentioned on the QWBSA. If the subject experienced symptoms that were not mentioned, s/he would fill in the circle corresponding to "Yes" and then write in the particular symptom(s) along with which of the past 3 days s/he experienced them.

Question 8c asks if the subject changed any plans or activities due to their health not already reported. If s/he did have to change plans/activities, s/he should write a description of the limitation(s) in the box provided.

Questions 9a-c instructs the subject to rate their overall health state in 3 different ways. First, on a 5 point scale from "poor" to "excellent." Second, a respondent compares current health to health of one year previous, and third to rate their health overall over the past 3 days on a 0 – 100 scale. Finally, Question 10 provides space for the respondent to provide information regarding gender, age, ethnicity, and education level.

A.2. Interviewer

The QWB-SA can be administered by telephone or in a face-to-face interview, though the psychometric properties of the QWB-SA administered by these methods have not been specifically studied. If an investigator finds it necessary to administer a QWB-SA by telephone or via an interviewer, the questions should be read exactly as they appear on the questionnaire. Caution in interpreting such data needs to be exercised.

Proxy

Assessment by proxy is not recommended for the QWB-SA but may be the only option for a subject who cannot comprehend all of the questions or cannot adequately communicate responses to the questions. For example, this option may be considered with subjects who are cognitively impaired (e.g., brain injury, dementia). The User is warned however that problems abound with data on subjective health states gathered by proxy. Psychometric properties of the QWB-SA administered by proxy have not been evaluated. Investigators may consider using the responses of a proxy to the QWB-SA in cases where a patient cannot respond on their own. However, given many of the symptoms assessed are subjective and personal in nature, and the impact of the use of a proxy lacks adequate psychometric testing, caution should be used when interpreting such data.

A.3. On-line

A web-based version of the QWB-SA is being developed and soon will be available on the Internet. Access codes and passwords providing access to the web-based QWB-SA will be available to researchers through the UCSD Health Outcomes Assessment Program. Identifying information will not be necessary and security measures are being implemented. Response data will be scored before being stored in a downloadable format and data for each research project will be stored separately.

B. Scoring

Scoring algorithms are available to all individuals and entities signing a QWB-SA copyright agreement. The QWB-SA may be used free of charge by non-profit organizations that provide evidence of their non-profit status and agree to provide a copy of relevant, non-identifiable project data with UCSD. For-profit organizations are required to sign a usage contract in addition to the copyright agreement. Fees for usage are dependent on volume, length of intended usage, mode of administration, and other factors, but are usually quite affordable.

The UCSD Health Outcomes Assessment Program provides complete data services for the administration, scoring, cleaning, and interpretation of the QWB-SA and other health outcome measures. (A computer software-scoring program is also available for a fee, under certain circumstances and pre-arranged with HOAP personnel.)

For more information, or to complete a copyright agreement and begin using the QWBSA, please contact the UCSD Health Outcomes Assessment Program at 9500 Gilman Dr. #0994, La Jolla, CA 92093-0994, or call 858-622-1771.

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QWB Data from Selected Studies

I. SHE study

Soy Health Effects Study (SHE) conducted under a National Institutes of Health grant to study the potential benefits of a dietary supplement of soy on the health of postmenopausal women. Subjects for the study consisted of women aged 45–74 y who attended screening and baseline visits and were subsequently enrolled in the Soy Health Effects (SHE) Study. The SHE Study is a randomized, double-blind, placebo-controlled trial designed to investigate the extent to which isoflavone use improves heart disease risk factors, bone density and quality of life in postmenopausal women. To be eligible for the SHE Study, women had to be at least 2 y postmenopausal, not using HRT for ≥ 3 mo, and not currently using lipid-lowering drugs, antidiabetic medications, tamoxifen, or soy protein or herbal supplements. Women with a history of uncontrolled hypertension, stroke or transient ischemic attack, cancer diagnosed <5 y ago, or myocardial infarction within 6 mo were excluded from the study. A total of 210 postmenopausal women were enrolled in the SHE study.

SHE study

	N	Minimum	Maximum	Mean	Std. Dev.
QWB-SA	210	.273	1.000	.694	.118
CPX	210	.000	.559	.294	.107
MOB	210	.000	.010	.000	.001
PAC	210	.000	.102	.010	.023
SAC	210	.000	.096	.002	.010
AGE	207	44	74	56.79	6.38

	N	%
Education		
8th grade	3	1.4
High school	17	8.1
Some college	87	41.6
College grad	51	24.4
Some grad schl	11	5.3
Graduate degr	40	19.1
Ethnicity		
Afr American	10	4.8
Asian/Pac. Isldr	10	4.8
Caucasian	163	78.0
Hispanic	23	11.0
Nat American	3	1.4

II. Cataract

Between July -November 1998 patients were selected from the practices of 9 ophthalmologists in a group practice of the Southern California Kaiser-Permanente Medical Group. All consecutive adult patients coming to cataract surgery were invited to participate.

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1. Rosen P, Kaplan B, David K. Measuring Outcomes of Cataract Surgery Using the Quality of Well-Being Scale and the VF-14. Journal of Cataract & Refractive Surgery.

Cataract baseline (pre – surgery scores)

	N	Minimum	Maximum	Mean	Std. Dev.
QWB-SA	288	.151	1.000	.595	.134
CPX	288	.000	.559	.359	.102
MOB	288	.000	.059	.003	.006
PAC	288	.000	.163	.034	.044
SAC	288	.000	.096	.009	.020
AGE	277	42	91	71.43	9.07

	N	%
Education		
8th grade	14	5.2
High school	84	31.2
Some college	87	32.3
College grad	38	14.1
Some grad schl	19	7.1
Graduate degr	27	10.0
Ethnicity		
Afr American	5	1.8
Asian/Pac. Isldr	11	4.0
Caucasian	224	82.1
Hispanic	14	5.1
Nat American	13	4.8
Other	6	2.2

III. DPP Study

The Diabetes Prevention Program s a large, multi-site, randomized, controlled clinical trial that compared the efficacy of an intensive lifestyle intervention to a glucose lowering drug and a placebo control. Between 1996 and 1999, 3234 non-diabetic persons who were at risk for developing diabetes were randomized to one of the 3 groups (1082 placebo, 1073 metformin (Glucophage), and 1079 lifestyle intervention).

Participants were recruited at 27 different sites nationwide. According to the study website " Volunteers were recruited from populations known to be at particularly high risk for impaired glucose tolerance and NIDDM including the following: persons with a family history of NIDDM, the elderly, overweight individuals, women with a history of diabetes during pregnancy ("gestational diabetes"), and minority populations including African Americans, Hispanic Americans, Asian and Pacific Island Americans, and Native Americans. In order to be eligible, persons who are older than 25 years will have to demonstrate impaired glucose tolerance with plasma glucose levels 95-125 mg/dL (5.3-6.9 mmol/L) fasting and 140-199 mg/dL (7.8 -11.0 mmol/L) two hours after a 75 gram oral glucose tolerance test. The study-wide goal is that approximately 50% of the study population be composed of minorities and approximately 20% be 65 years of age or older"(1).

References

1. The Diabetes Prevention Program Research Group. Within-trial cost-effectiveness of lifestyle intervention or metformin for the primary prevention of type 2 diabetes. Diabetes Care. 2003 Sep;26(9):2518-23.
2. The Diabetes Prevention Program. Design and methods for a clinical trial in the prevention of type 2 diabetes. Diabetes Care. 1999 Apr;22(4):623-34.
3. The DPP Research Group. Reduction in the incidence of type 2 diabetes with lifestyle intervention or metformin. New England Journal of Medicine 2002 Feb; 346(6);393-403.

DPP Study.

	N	Minimum	Maximum	Mean	Std. Dev
QWB	3234	.312	1.0	.681	.108
CPX	3234	0	.559	.303	.093
MOB	3234	0	.089	.001	.004
PAC	3234	0	.163	.014	.028
SAC	3234	0	.096	.002	.009

	N	%
Education		
8th grade	53	6
High school	147	17
Some college	265	31
College grad	167	19
Some grad schl	63	7
Graduate degr	168	20
Ethnicity		
Afr American	176	20
Asian/Pac. Isldr	16	2
Caucasian	462	54
Hispanic	127	15
Nat American	58	7
Other	23	3

IV. Validation of the QWB-SA in Musculoskeletal Disease

This project was conducted as part of the UCSD Multipurpose Arthritis Center and the primary goal was to demonstrate the construct validity of the QWB-SA in persons with musculoskeletal disease and to compare them to family medicine patients without arthritis. Individuals with arthritis were recruited from three rheumatology clinics in the San Diego area, while family medicine patients were recruited from four family medicine clinics in the San Diego area.

The study examined the relationships between the score obtained with the QWB with those obtained using disease specific paper and pencil measures. Second, the study compared people with arthritis to people visiting family medicine clinics for a variety of reasons other than arthritis. Research assistants approached potential subjects in the waiting rooms of the cooperating clinics. Potential subjects were told that the purpose of the study was to validate a quality of life measure for persons with arthritis, and that participation would involve completing a set of questionnaires. Interested individuals approached in family medicine clinics were asked if they had ever been diagnosed with rheumatoid arthritis, osteoarthritis, fibromyalgia, lupus, or another musculoskeletal disease. Patients reporting one of the above diagnoses were grouped with arthritis patients rather than family medicine subjects. Musculoskeletal diagnoses for participants recruited from rheumatology clinics were obtained from their physicians.

References

Frosch D, Kaplan RM, Ganiats TG, Groessl EJ, Sieber WJ, Weisman M. Validity of self-administered quality of well-being scale in musculoskeletal disease. Arthritis and Rheumatism.

MAC Study (non-arthritic controls)

	N	Minimum	Maximum	Mean	Std. Dev.
QWB	352	.260	1.0	.643	.135
CPX	352	0	.559	.322	.101
MOB	352	0	.089	.002	.008
PAC	352	0	.163	.022	.039
SAC	352	0	.096	.011	.090

	N	%
Education		
8th grade	4	1
High school	24	7
Some college	112	32
College grad	83	24
Some grad schl	35	10
Graduate degr	89	26
Ethnicity		
Afr American	19	6
Asian/Pac. Isldr	28	8
Caucasian	251	73
Hispanic	28	8
Nat American	4	1
Other	16	5

MAC Study (Arthritis patients)

	N	Minimum	Maximum	Mean	Std. Dev.
QWB	220			.497	.154
CPX	220	0	.559	.385	.108
MOB	220	0	.059	.003	.008
PAC	220	0	.163	.066	.049
SAC	220	0	.096	.027	.029

	N	%
Education 8th grade	8	4
High school	26	12
Some college	86	39
College grad	51	23
Some grad schl	14	6
Post graduate	34	16
Ethnicity		
Afr American	13	6
Asian/Pac. Isldr	14	6
Caucasian	161	74
Hispanic	16	7
Nat American	9	4
Other	5	2

V. Glycemia and Quality of well-being in patients with diabetes

The study used the QWB-SA to explore the relationship between measures of glycemia and health-related quality of life. Glycemia was measured with self-reported frequency of symptomatic hypoglycemia and hyperglycemia, and HbA1c. HRQOL and health utility scores were assessed with the QWB-SA.

As described in the study methods, the sample "included 1522 patients: 634 with type 1 diabetes and 888 with type 2 diabetes who attended endocrinology, diabetes, and ophthalmology clinics at the University of Michigan Health System between June 29,1998 and March 15,2001 and had HbA1c measurements on the day of the visit. All patients were over 18 years of age or older, able to give informed consent, and able to either self-administer the questionnaires or, if visually impaired, to respond to a research assistant reading the questionnaires"

References

1. Tabaei BP, Shill-Novak J, Brandle M, Burke R, Kaplan RM, Herman WH. Glycemia and the quality of well-being in patients with diabetes, Quality of Life Research (in press).
2. Coffey JT, Brandle M, Zhou H, Marriott D, Burke R, Tabaei BP, Engelgau MM, Kaplan RM, Herman WH. Valuing health-related quality of life in diabetes. Diabetes Care. 2002 Dec;25(12):2238-43.

VI. Depressed inpatients & outpatients

A convenience sample of 39 inpatients and 19 outpatients from the San Diego VA diagnosed with current Major Depressive Episode. Participants were 78% male with an average age of 46 (range 20-70). While the study demonstrated strong sensitivity of the QWB-SA to depression severity, the results reported here are for baseline only. Data is reported on inpatients and outpatients separately, with no data on separate QWB-SA component scores.

Reference:

1. Pyne, J.M., Sieber, W.J., David, K., Kaplan, R.M., Rapaport, M.H., and Williams, D.K. (2003). Use of the Quality of Well-Being – Self-Administered version (QWB-SA) in assessing health-related quality of life in depressed patients. Journal of Affective Disorders, 76, 237-247.

VA depressed inpatients

	N	Minimum	Maximum	Mean	Std. Dev.
QWB-SA	39	- -	- -	.383	.118

VA depressed outpatients

	N	Minimum	Maximum	Mean	Std. Dev.
QWB-SA	19	- -	- -	.479	.115

VII. Migraine

A total of 89 adults (87% women) living in Canada were recruited by a market research firm; all were known to suffer migraine headaches. Each participant completed both the interviewer-administered QWB and the QWB-SA on non-headache as well as on headache days. Mean age was 42 (range 36 to 64).

Reference:

Sieber, W.J., David, K , Adams, J., Kaplan, R.M. and. Ganiats, T.G. (2000). Assessing the Impact of migraine on health-related quality of life: An additional use of the Quality of Well-Being Scale -Self-Administered (QWB-SA). Headache, 40(8), 662-671

Migraine Study (headache days)

	N	Minimum	Maximum	Mean	Std. Dev.
QWB	89	- -	- -	.492	.157
CPX	89	- -	- -	.406	.009
MOB	89	- -	- -	.004	.011
PAC	89	- -	- -	.067	.070
SAC	89	- -	- -	.031	.028

Migraine Study (non-headache days)

	N	Minimum	Maximum	Mean	Std. Dev.
QWB	89	- -	- -	.628	.149
CPX	89	- -	- -	.337	.013
MOB	89	- -	- -	.001	.005
PAC	89	- -	- -	.025	.047
SAC	89	- -	- -	.009	.020

QWB-SA preference weights

Preference weights for each item on the QWB-SA (in order of presentation on **questionnaire)**

Symptoms (CPX)

blindness, or severely impaired vision in both eyes	.523
blindness or severely impaired vision in only one eye	.358
speech problems such as stuttering, or being unable to speak clearly	.358
missing or paralyzed hands, feet, arms or legs	.423
missing or paralyzed fingers or toes	.297
any deformity of the face, fingers, hand/arm, foot /leg, or back	.408
general fatigue, tiredness or weakness	.256
a problem with unwanted weight gain or weight loss	.233
a problem with being under or over weight	.225
problems chewing your food adequately	.204
any hearing loss or deafness	.274
any noticeable skin problems (i.e., bad acne, large burns or scars)	.187
eczema or burning/itching rash	.187
health aides used:	
dentures.153	
eye glasses or contact lenses	.066
hearing aide	.148
any problems with your vision not corrected with glasses or contact lenses	.293
any eye pain, irritation, discharge, or excessive sensitivity to light	.389
a headache	.189

dizziness, earache or ringing in your ears	.299
difficulty hearing or discharge or bleeding from an ear	.350
stuffy or runny nose or bleeding om the nose	.178
a sore throat, difficulty swallowing, or hoarse voice?	.204
a tooth ache or jaw pain	.298
sore or bleeding lips, tongue, or gums	.271
coughing or wheezing	.386
shortness of breath or difficulty breathing	.208
chest pain, pressure, palpitations, fast or skipped heart beat or other discomfort in the chest	.343
an upset stomach, abdominal pain, nausea, heart burn or vomiting	.260
difficulty with bowel movements, diarrhea, constipation, rectal bleeding, black tar-like stools, or any pain or discomfort in the rectal area or pain, burning, or blood in urine	.278 .424
loss of bladder control, frequent night-time urination or difficulty with urination	.259
genital pain, itching, burning, or abnormal discharge, or pelvic cramping or abnormal bleeding (does not include normal menstruation).	.369
broken arm, wrist, foot, leg, or other broken bone (other than in back)	.365
pain, stiffness, cramps, weakness or numbness in the neck or back	.318
pain, stiffness, cramps, weakness or numbness in the hips or sides	.365
pain, stiffness, cramps, weakness or numbness in any of the joints or muscles of the hand, feet, arms or legs	.318
swelling of ankles, hands, feet, or abdomen	.306
fever, chills, or sweats	.320

loss of consciousness, fainting, or seizures	.517
difficulty with your balance, standing or walking	.377
trouble falling asleep or staying asleep	.296
spells of feeling nervous or shaky	.286
spells of feeling upset, downhearted, or blue	.327
excessive worry or anxiety	.324
feelings that you had little or no control over events in your life	.430
feelings of being lonely or isolated	.311
feelings of frustration, irritation or close to losing your temper	.378
a hangover	.297
any decrease of sexual interest or perormance	.307
Confusion, difficulty understanding the written or spoken word, or significant memory loss	.559
thoughts or images you could not get out of your mind	.255
take any medication including over-the-counter remedies (aspirin/Tylenol, allergy medications, insulin, hormones, estrogen, thyroid, prednisone)	.160
to stay on a medically prescribed diet for health reasons	.201
a loss of appetite or over-eating	.223
Mobility	
spend any part of the day or night as a patient in a hospital, nursing home, or rehabilitation center	.089
either not drive a motor vehicle or not use public transportation because of your health or need help from another person to use	.031
Physical Activity	

have trouble climbing stairs or inclines or walking off the curb	.072
avoid or have trouble walking, or walk more slowly than other people your age	.072
limp 0 use a cane, crutches or walker	.072
avoid or have trouble bending over, stooping or kneeling	.072
have any trouble lifting or carrying everyday objects such as books, a briefcase or groceries.	.072
have any other limitations in physical movements	.072
spend all or most of the day in a bed, chair or couch	.163
spend all or most of the day in a wheelchair	.102
If in wheelchair, someone else controlled its movement	.163
Social & Self-care activity	
need help with your personal care needs, such as eating, dressing, bathing, or getting around our home	.096
avoid, need help with, or were limited in doing some of your usual activities, such as work, school, or housekeeping?	.054
avoided or felt limited in doing some of your usual activities. such as visiting family or friends, hobbies, recreational, or religious activities	.054

Quality of Well-Being Scale, Self-Administered, QWB-SA, V1.04

This survey asks about health problems that you have experienced in the last 3 days, not including today. Please answer all questions by filling in the appropriate circle with blue or black ink. Please do not use check marks or use felt tip pens. Thank you.

Today's date: ☐☐ / ☐☐ / ☐☐ (MM / DD / YY)

Part I - Acute and Chronic Symptoms

1. Please indicate whether you currently experience each of the following health symptoms or problems

Do you have....

a. blindness or severely impaired vision in both eyes? Y○ N○
blindness or severely impaired vision in only one eye? Y○ N○
b. speech problems such as stuttering, or being unable to speak clearly? Y○ N○
c. missing or paralyzed hands, feet, arms, or legs? Y○ N○
missing or paralyzed fingers or toes? Y○ N○
d. any deformity of the face, fingers, hand or arm, foot or leg, or back (e.g. severe scoliosis)? Y○ N○
e. general fatigue, tiredness, or weakness? Y○ N○
f. a problem with unwanted weight gain or weight loss? Y○ N○
g. a problem with being under or over weight? Y○ N○
h. problems chewing your food adequately? Y○ N○
i. any hearing loss or deafness? Y○ N○
j. any noticeable skin problems, such as bad acne or large burns or scars on face, body, arms, or legs? Y○ N○
k. eczema or burning/itching rash? Y○ N○

Which of the following health aides do you use/have?

dentures? Y○ N○
oxygen tank? Y○ N○
prosthesis? Y○ N○
eye glasses or contact lenses? Y○ N○
hearing aide? Y○ N○
magnifying glass? Y○ N○
neck, back, or leg brace? Y○ N○

2. For the following list of problems indicate which days (if any) over the past 3 days, not including today, you had the problem. If you have not had the symptom in the past 3 days, do not leave the question blank, please fill in "no days." If you have experienced the symptom in the past 3 days, please check which of the days you had it; if you experienced it on more than one of the days, fill in all days that apply.

For example, if you had a headache yesterday and the day before that:
A headache?
○ No Days ● Yesterday ● 2 days ago ○ 3 days ago

Did you have.... (please fill in all days that apply)

a. any problems with your vision not corrected with glasses or contact lenses (such as double vision, distorted vision, flashes, or floaters)?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

b. any eye pain, irritation, discharge, or excessive sensitivity to light?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

c. a headache?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

d. dizziness, earache, or ringing in your ears?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

e. difficulty hearing, or discharge, or bleeding from an ear?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

f. stuffy or runny nose, or bleeding from the nose?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

g. a sore throat, difficulty swallowing, or hoarse voice?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

h. a tooth ache or jaw pain?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

i. sore or bleeding lips, tongue, or gums?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

j. coughing or wheezing?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

k. shortness of breath or difficulty breathing?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

Did you have.... (please fill in all days that apply)

l. chest pain, pressure, palpitations, fast or skipped heart beat, or other discomfort in the chest?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

m. an upset stomach, abdominal pain, nausea, heartburn, or vomiting?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

n. difficulty with bowel movements, diarrhea, constipation, rectal bleeding, black tar-like stools, or any pain or discomfort in the rectal area?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

o. pain, burning, or blood in urine?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

p. loss of bladder control, frequent night-time urination, or difficulty with urination?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

q. genital pain, itching, burning, or abnormal discharge, or pelvic cramping or abnormal bleeding? (does not include normal menstruation)
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

r. a broken arm, wrist, foot, leg, or any other broken bone (other than in the back)?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

s. pain, stiffness, cramps, weakness, or numbness *in the neck or back?*
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

t. pain, stiffness, cramps, weakness, or numbness *in the hips or sides?*
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

u. pain, stiffness, cramps, weakness, or numbness in any *of the joints or muscles of the hand, feet, arms, or legs?*
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

v. swelling of ankles, hands, feet or abdomen?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

w. fever, chills, or sweats?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

x. loss of consciousness, fainting, or seizures?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

y. difficulty with your balance, standing, or walking?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

3. The following symptoms are about your feelings, thoughts, and behaviors. Please fill in which days (if any) over the past 3 days, not including today, you have had ...

a. trouble falling asleep or staying asleep?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

b. spells of feeling nervous or shaky?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

c. spells of feeling upset, downhearted, or blue?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

d. excessive worry or anxiety?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

e. feelings that you had little or no control over events in your life?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

f. feelings of being lonely or isolated?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

g. feelings of frustration, irritation, or close to losing your temper?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

h. a hangover?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

i. any decrease of sexual interest or performance?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

j. confusion, difficulty understanding the written or spoken word, or significant memory loss?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

k. thoughts or images you could not get out of your mind?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

l. to take any medication including over-the-counter remedies (aspirin/tylenol, allergy medications, insulin, hormones, estrogen, thyroid, prednisone)?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

Please continue on other side.

Participant ☐☐☐☐☐☐☐☐☐☐

Quality of Well-Being Scale, Self-Administered, QWB-SA, V1.04 - Page 2

Part I - Acute and Chronic Symptoms (continued)

3. Question 3 continued .....

m. to stay on a medically prescribed diet for health reasons?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

n. a loss of appetite or over-eating?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

4. In the last 3 days did you have any symptoms, health complaints, or pains that have not been mentioned?

○ Yes ○ No

If yes, what were they and on which days did you have them?

	Symptoms	Days
A.	_____	
B.	_____	

Part II - Self Care

5. *Over the last 3 days ... (please fill in all days that apply)*

a. did you spend any part of the day or night as a patient in a hospital, nursing home, or rehabilitation center?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

b. because of any impairment or health problem, did you need help with your personal care needs, such as eating, dressing, bathing, or getting around your home?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

Part III - Mobility

6. Over the last 3 days ... (please fill in all days that apply)

a. which days did you drive a motor vehicle?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

b. which days did you use public transportation such as a bus, subway, Medi-van, train, or airplane?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

c. which days did you either not drive a motor vehicle or not use public transportation because of your health, or need help from another person to use?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

Part IV - Physical Activity

7. Over the last 3 days did you ... (please fill in all days that apply)

a. have trouble climbing stairs or inclines or walking off the curb?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

b. avoid walking, have trouble walking, or walk more slowly than other people your age?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

c. limp or use a cane, crutches, or walker?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

d. avoid or have trouble bending over, stooping, or kneeling?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

e. have any trouble lifting or carrying everyday objects such as books, a briefcase, or groceries?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

f. have any other limitations in physical movements?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

g. spend all or most of the day in a bed, chair, or couch because of health reasons?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

h. spend all or most of the day in a wheelchair?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

If in a wheelchair, on which days did someone else control its movement?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

Part V - Usual Activity

8. *Over the last 3 days ... (please fill in all days that apply)*

a. because of any physical or emotional health reasons, on which days did you avoid, need help with, or were limited in doing some of your usual activities, such as work, school or housekeeping?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

b. because of any physical or emotional health reasons, on which days did you avoid or feel limited in doing some of your usual activities, such as visiting family or friends, hobbies, shopping, recreational, or religious activities?
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

c. on which days did you have to change any of your plans or activities because of your health? (Consider only activities that you did not report in the last 2 questions.)
○ No Days ○ Yesterday ○ 2 days ago ○ 3 days ago

If limited, please describe:

9a. Would you say that your health is:
○ Excellent ○ Very Good ○ Good ○ Fair ○ Poor

b. Compared to a year ago, how would you rate your health in general now:
○ Much better than a year ago
○ Somewhat better than one year ago
○ About the same as a year ago
○ Somewhat worse than a year ago
○ Much worse than a year ago

c. Think about a scale of 0 to 100, with zero being the least desirable state of health that you could imagine and 100 being perfect health. What number, from 0 to 100 would you give to the state of your health, on average, over the last 3 days?

0	10	20	30	40	50	60	70	80	90	100
○	○	○	○	○	○	○	○	○	○	○

10. **Please complete the following questions:**

Sex: ○ Male ○ Female

Age: ☐☐

What is your ethnicity?
○ African American
○ Asian/Pacific Islander
○ Caucasian - Non Hispanic
○ Hispanic
○ Native American
○ Other

Which of the following best describes your educational background?
○ 8th Grade Graduate
○ High School Graduate
○ Some College
○ College Graduate (B.S. or B.A. degree)
○ Some Graduate School
○ Completed Post-Graduate (M.A., M.D., Ph.D.)

Thank you for completing the QWB SA 1.04 Health Status Survey

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Protocol Number ☐☐☐☐☐☐

Investigator Number ☐☐☐

Participant ☐☐☐☐☐☐☐☐☐☐

Clinic: | Participant ID: | Nickname: | Outcome Visit: | Month: | Day: | Year:

Quality of Well-Being Scale, Self-Administered (QWB-SA), V1.04

This survey asks about health problems that you have experienced in the last 3 days, not including today.
Please answer all questions by filling in the appropriate circle completely with blue or black ink.
Please do not use check marks or felt tip pens. Thank you.

1. Please indicate whether you currently experience each of the following health symptoms or problems:

Do you have…	**YES**	**NO**
a. blindness or severely impaired vision in both eyes?	O	O
blindness or severely impaired vision in only one eye?	O	O
b. speech problems such as stuttering, or being unable to speak clearly?	O	O
c. missing or paralyzed hands, feet, arms, or legs?	O	O
missing or paralyzed fingers or toes?	O	O
d. any deformity of the face, fingers, hand or arm, foot or leg, or back (e.g. severe scoliosis)?	O	O
e. general fatigue, tiredness, or weakness?	O	O
f. a problem with unwanted weight gain or weight loss?	O	O
g. a problem with being under or over weight?	O	O
h. problems chewing your food adequately?	O	O
i. any hearing loss or deafness?	O	O
j. any noticeable skin problems, such as bad acne or large burns or scars on face, body, arms, or legs?	O	O
k. eczema or burning/itching rash?	O	O

Which of the following health aides do you use/have?	**YES**	**NO**
a. dentures?	O	O
b. oxygen tank?	O	O
c. prosthesis?	O	O
d. eye glasses or contact lenses?	O	O
e. hearing aide?	O	O
f. magnifying glass?	O	O
g. neck, back, or leg brace?	O	O

2. For the following list of problems, indicate which days (if any) over the past 3 days, not including today, you had the problem. If you have not had the symptom in the past 3 days, do not leave the question blank, please fill in "no days." If you have experienced the symptom in the past 3 days, please fill in which of the days you had it; if you experienced it on more than one of the days, please fill in all days that apply.

	No days	**Yester-day**	**2 days ago**	**3 days ago**
For example, if you had a headache yesterday and the day before that, you would mark for a headache:	O	●	●	O
Did you have…(please fill in all days that apply) a. any problems with your vision not corrected with glasses or contact lenses (such as double vision, distorted vision, flashes, or floaters)?	O	O	O	O
b. any eye pain, irritation, discharge, or excessive sensitivity to light?	O	O	O	O

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Clinic: | Participant ID: | Nickname: | Outcome Visit: | Month: | Day: | Year:

Did you have… (please fill in all days that apply)	No days	Yester–day	2 days ago	3 days ago
c. a headache?	O	O	O	O
d. dizziness, earache, or ringing in your ears?	O	O	O	O
e. difficulty hearing, or discharge, or bleeding from an ear?	O	O	O	O
f. stuffy or runny nose, or bleeding from the nose?	O	O	O	O
g. a sore throat, difficulty swallowing, or hoarse voice?	O	O	O	O
h. a tooth ache or jaw pain?	O	O	O	O
i. sore or bleeding lips, tongue, or gums?	O	O	O	O
j. coughing or wheezing?	O	O	O	O
k. shortness of breath or difficulty breathing?	O	O	O	O
l. chest pain, pressure, palpitations, fast or skipped heart beat, or other discomfort in the chest?	O	O	O	O
m. an upset stomach, abdominal pain, nausea, heartburn, or vomiting?	O	O	O	O
n. difficulty with bowel movements, diarrhea, constipation, rectal bleeding, black tar-like stools, or any pain or discomfort in the rectal area?	O	O	O	O
o. pain, burning, or blood in urine?	O	O	O	O
p. loss of bladder control, frequent night-time urination, or difficulty with urination?	O	O	O	O
q. genital pain, itching, burning, or abnormal discharge, or pelvic cramping or abnormal bleeding (does not include normal menstruation)?	O	O	O	O
r. a broken arm, wrist, foot, leg, or any other broken bone (other than in the back)?	O	O	O	O
s. pain, stiffness, cramps, weakness, or numbness *in the neck or back*?	O	O	O	O
t. pain, stiffness, cramps, weakness, or numbness *in the hips or sides*?	O	O	O	O
u. pain, stiffness, cramps, weakness, or numbness in any *of the joints or muscles of the hand, feet, arms, or legs*?	O	O	O	O
v. swelling of ankles, hands, feet, or abdomen?	O	O	O	O
w. fever, chills, or sweats?	O	O	O	O
x. loss of consciousness, fainting, or seizures?	O	O	O	O
y. difficulty with your balance, standing, or walking?	O	O	O	O

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Clinic: | Participant ID: | Nickname: | Outcome Visit: | Month: | Day: | Year:

Did you have… (please fill in all days that apply)	No days	Yester-day	2 days ago	3 days ago
3. The following symptoms are about your feelings, thoughts, and behaviors. Please fill in which days (if any) over the past 3 days, not including today, you have had…				
a. trouble falling asleep or staying asleep?	O	O	O	O
b. spells of feeling nervous or shaky?	O	O	O	O
c. spells of feeling upset, downhearted, or blue?	O	O	O	O
d. excessive worry or anxiety?	O	O	O	O
e. feelings that you had little or no control over events in your life?	O	O	O	O
f. feelings of being lonely or isolated?	O	O	O	O
g. feelings of frustration, irritation, or close to losing your temper?	O	O	O	O
h. a hangover?	O	O	O	O
i. any decrease of sexual interest or performance?	O	O	O	O
j. confusion, difficulty understanding the written or spoken word, or significant memory loss?	O	O	O	O
k. thoughts or images you could not get out of your mind?	O	O	O	O
l. to take any medication including over-the-counter remedies (aspirin/tylenol, allergy medications, insulin, hormones, estrogen, thyroid, prednisone)?	O	O	O	O
m. to stay on a medically prescribed diet for health reasons?	O	O	O	O
n. a loss of appetite or over-eating?	O	O	O	O
4. In the last 3 days did you have any symptoms, health complaints, or pains that have not been mentioned? O Yes O No If yes, what were they and on which days did you have them?				
Symptom A:_____	O	O	O	O
Symptom B:_____	O	O	O	O

Over the last 3 days…(please fill in all days that apply)	No days	Yester-day	2 days ago	3 days ago
5a. did you spend any part of the day or night as a patient in a hospital, nursing home, or rehabilitation center?	O	O	O	O
5b. because of any impairment or health problem, did you need help with your personal care needs, such as eating, dressing, bathing, or getting around your home?	O	O	O	O
6a. which days did you drive a motor vehicle?	O	O	O	O
6b. which days did you use public transportation such as a bus, subway, Medi-van, train, or airplane?	O	O	O	O
6c. which days did you either not drive a motor vehicle or not use public transportation because of your health, or need help from another person to use?	O	O	O	O

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Clinic: | Participant ID: | Nickname: | Outcome Visit: | Month: | Day: | Year:

Over the last three days, did you… (please fill in all days that apply)	No days	Yester–day	2 days ago	3 days ago
7a. have trouble climbing stairs or inclines or walking off the curb?	O	O	O	O
7b. avoid walking, have trouble walking, or walk more slowly than other people your age?	O	O	O	O
7c. limp or use a cane, crutches, or walker?	O	O	O	O
7d. avoid or have trouble bending over, stooping, or kneeling?	O	O	O	O
7e. have any trouble lifting or carrying everyday objects such as books, a briefcase, or groceries?	O	O	O	O
7f. have any other limitations in physical movements?	O	O	O	O
7g. spend all or most of the day in a bed, chair, or couch because of health reasons?	O	O	O	O
7h. spend all or most of the day in a wheelchair?	O	O	O	O
If in a wheelchair, on which days did someone else control its movement?	O	O	O	O
8a. because of any physical or emotional health reasons, on which days did you avoid, need help with, or were limited in doing some of your usual activities, such as work, school, or housekeeping?	O	O	O	O
8b. because of physical or emotional health reasons, on which days did you avoid or feel limited in doing some of your usual activities, such as visiting family or friends, hobbies, shopping, recreational, or religious activities?	O	O	O	O
8c. on which days did you have to change any of your plans or activities because of your health? (Consider only activities that you did not report in the last 2 questions.)	O	O	O	O

9a. Would you say that your health is:
- O Excellent
- O Very Good
- O Good
- O Fair
- O Poor

9b. Compared to a year ago, how would you rate your health in general now?
- O Much better now than a year ago
- O Somewhat better now than one year ago
- O About the same as a year ago
- O Somewhat worse than a year ago
- O Much worse than a year ago

9c. Think about a scale of 0 to 100, with zero being the least desirable state of health that you could imagine and 100 being perfect health. What number from 0 to 100 would you give to the state of your health, on average, over the last 3 days?

0	10	20	30	40	50	60	70	80	90	100
O	O	O	O	O	O	O	O	O	O	O

10a. Sex: O Male O Female

10b. Age in Years: ☐☐☐

10c. What is your ethnicity?
- O African American
- O Asian/Pacific Islander
- O Caucasian – Non Hispanic
- O Hispanic
- O Native American
- O Other

10d. Which of the following best describes your educational background?
- O 8th Grade Graduate
- O High School Graduate
- O Some College
- O College Graduate (B.S. or B.A. degree)
- O Some Graduate School
- O Completed Post-Graduate (M.A.,M.D.,Ph.D.)

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9500 GILMAN DRIVE, #0994
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QUEBEC USER EVALUATION OF SATISFACTION WITH ASSISTIVE TECHNOLOGY

The Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) is a structured and standardized measure to evaluate user satisfaction with a wide range of technology devices. The concept of satisfaction that it measures is made up of both factors related to the assistive technology device and the service process surrounding it. The individual rates each item with regard to the degree of satisfaction and the also the importance they ascribe to it.

Abbreviated Name: QUEST 2.0
Author(s): L. Demers, R. Weiss-Lambrou & B. Ska
Purpose: Outcome measure for assistive technology devices
Population: Adult
Type of Instrument: Utility
Mode of Administration:

Rater:	Self-administered
Time required:	10-15 minutes
Response Options:	Likert scale
Scoring:	Global score
Score Direction:	Higher scores show better QoL

Number of Items: 12
Original Language: English

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Contact for information and permission to use:

Louise Demers Ph.D. OT(C)
Researcher
Research Center, Montreal Geriatric University Institute
4565 Queen Mary Road, Montréal (Quebec), H3W 1W5
Phone: (514) 340-3540 x3010
Fax: (514) 340-3548

Assistant Professor
School of Rehabilitation, Medicine Faculty, Université de Montréal
C.P. 6128, Succ. Downtown, Montreal (Québec), H3C 3J7
Phone: (514) 343-6111 x4397
Fax: (514) 343-2105

Dr Marcia J. Scherer
The Institute for Matching a Person & Technology
486 Lake Road, Webster, NY 14580
716-671-3461 (phone/fax)
D-U-N-S Number 01-293-5933
Email: IMPT97@aol.com

Dimensions covered by the questionnaire :

- Assistive device (8 items)
- Services (4 items)

Key References:

1. Demers L, Weiss-Lambrou R, Ska B. Development of the Quebec User Evaluation of Satisfaction with assistive Technology (QUEST). Assist Technol 1996;8:3-13.

This study's purpose was to develop a clinical instrument designed to evaluate user satisfaction with assistive technology devices. This paper describes the methodology used to develop the instrument entitled the Quebec User Evaluation of Satisfaction with assistive Technology (QUEST). Based on the theoretical and practical foundations of assistive technology as well as on the concept of satisfaction, preliminary versions of the instrument were created and examined by a panel of team participants. After the panel's recommendations were incorporated, a pretest of the revised instrument was conducted and the final French version of QUEST emerged. The originality of QUEST lies in its inter-activeness and user-directed approach to assessing satisfaction with assistive technology. From a set of 27 variables, the user is asked to indicate the degree of importance he/she attributes to each of the satisfaction variables and then to rate his/her degree of satisfaction with each of the variables considered (quite or very) important. While QUEST remains a clinical instrument undergoing pilot testing, it holds much promise in our quest for a reliable and valid means of assessing assistive technology outcome from the user's perspective.

2. Demers L, Weiss-Lambrou R, Ska B. Item analysis of the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST). Assist Technol 2000;12:96-105.

The Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) is an outcomes assessment tool designed to measure satisfaction with assistive technology in a structured and standardized way. The purpose of this article is to present the results of an analysis of the 24 items comprising QUEST and to explain how a subset of items demonstrating optimal measurement performance was selected. The criteria against which the items were measured were general acceptability, content validity, contribution to internal consistency, test-retest stability, and sensitivity. The items that ranked best in terms of these measurement properties were submitted to factorial analysis in order to complete the item selection. The first series of analyses reduced the item pool approximately by half, and the second series of analyses led to the final selection of 12 items. Factor analysis results suggested a bidimensional structure of satisfaction with assistive technology related to the assistive technology device (eight items) and services (four items). The 12-item revised version that will result from this study should prove to be a reliable and valid instrument for measuring outcomes in the field of assistive technology.

3. Demers L, Wessels R, Weiss-Lambrou R, Ska B, De Witte LP. Key dimensions of client satisfaction with assistive technology: a cross-validation of a Canadian measure in The Netherlands. J Rehabil Med 2001;33:187-91.

The purpose of this study was to conduct a cross-validation of the bidimensional structure of a satisfaction measure with assistive technology. Data were drawn from a follow-up study of 243 subjects who had been administered the Dutch version of the Quebec User Evaluation of Satisfaction with assistive Technology (QUEST). Ratings related to 12 satisfaction items were analysed. Factor analysis results showed that the underlying structure of satisfaction with assistive technology consists of two dimensions related to assistive technology, Device (eight items) and Services (four items), accounting for 40% of the common variance. This finding was consistent with a previous Canadian study and was interpreted as supporting the adequacy and stability of the QUEST measure of satisfaction. Although the structure is delineated, further studies are recommended to support its use in European countries.

4. Demers L, Monette M, Lapierre Y, Arnold DL, Wolfson C. Reliability, validity, and applicability of the Quebec User Evaluation of Satisfaction with assistive Technology (QUEST 2.0) for adults with multiple sclerosis. Disabil Rehabil 2002; 24:21-30.

Purpose: To investigate the measurement properties of the Quebec User Evaluation of Satisfaction with assistive Technology (QUEST 2.0) with respect to test-retest stability, alternate form reliability, construct validity and applicability. Method: Data on satisfaction and quality of life impacts of mobility devices were obtained from 81 community-based adults with Multiple Sclerosis, using the QUEST 2.0 and the Psychosocial Impact of Assistive Devices Scale (PIADS). Subjects were assigned to four groups and a second QUEST 2.0 was administered one week later. Groups differed with respect to the format and the

order in which alternate forms were presented. Measures of association were calculated between QUEST 2.0 and PIADS (n = 81) and between QUEST 2.0 alternate forms (n = 48). Respondents' reactions were considered. Results: The device subscale, services subscale, and total QUEST 2.0 scores achieved good test-retest stability (ICC 0.82, 0.82, 0.91). Alternate-form equivalence (ICC 0.89, 0.76, 0.91) was lower for services. The positive correlations between QUEST 2.0 and the three PIADS dimensions were fair to moderate for device and total QUEST 2.0 (r(p) 0.34 to 0.45) and fair with services (r(p) 0.27 to 0.30). The tool was positively received, with some restrictions for the services subscale. Conclusions: These findings on the psychometric properties of the QUEST 2.0 reinforce the relevance of the device subscale as an important outcome measure for assistive technology MS users. Further assessment of the services subscale is needed.

5. Demers L, Weiss-Lambrou R, Ska B. The Quebec User Evaluation of Satisfaction with assistive Technology (QUEST 2.0): An overview and recent progress. Technology and Disability.
6. Demers L, Wessels R, Weiss-Lambrou R, Ska B, & de Witte L. An international content validation of the Quebec User Evaluation of Satisfaction with assistive Technology (QUEST). Occupational Therapy International 1999; 6:159-175.
7. Demers L, Ska B, Giroux F, & Weiss-Lambrou R. Stability and reproducibility of the Quebec User Evaluation of Satisfaction with assistive Technology (QUEST). Journal of Rehabilitation Outcomes Measurement 1999; 3:42-52.

Quebec User Evaluation of Satisfaction with assistive Technology

QUEST version 2.0

An outcome measure for assistive technology devices

by

Louise Demers, Rhoda Weiss-Lambrou & Bernadette Ska

Introduction

The Quebec User Evaluation of Satisfaction with assistive Technology (QUEST) is a new outcome measurement instrument designed to evaluate a person's satisfaction with his or her assistive technology device. It can be used with adolescents, adults and elderly persons who as a result of a physical or sensory impairment have acquired an assistive technology device. The assistive devices targeted include seating and mobility aids environmental control units, hearing and visual aids as well as aids to assist in the performance of daily living activities. The concept of satisfaction as defined in QUEST refers to a person's positive or negative evaluation of those distinct dimensions of the assistive device that are influenced by one's expectations, perceptions, attitudes and personal values. It is important to note that QUEST does not assess the user's performance with the aid. Rather, its focus is on how satisfied the person is with specific features of the assistive technology device as well as certain characteristics of the services related to the technology.

The QUEST 2.0 is the result of the doctoral research conducted by Louise Demers and her research directors, Professors Rhoda Weiss-Lambrou and Bernadette Ska. It is a product of more than four years of research and development. Although there are some general satisfaction questionnaires and checklists that have been developed (Rehabilitation Engineering and Assistive Technology Society of North America, 1998), QUEST is the first and only standardized satisfaction assessment tool that was designed specifically for assistive technology devices. In developing the instrument, data from several sources contributed to item generation including Batavia and Hammer's evaluation criteria (1990). Scherer's *Matching a Person with Technology* (MPT) model (1996) served as the theoretical foundation for the instrument.

The QUEST 2.0 was created for assistive technology practitioners and researchers (i.e. occupational and physical therapists, speech pathologists, psychologists, and rehabilitation engineers). Designers, manufacturers and vendors of assistive technology devices can also use it. This new version of the assessment tool is in a paper and pencil format that can be either self-administered or completed with the help of the evaluator. As a clinical tool, the QUEST 2.0 provides practitioners with a means of collecting satisfaction data that can be used to document the real-life benefits of assistive technology and to justify the need for these devices. As a research tool, it can be used to compare satisfaction data with other outcome measures such as clinical results, quality of life, functional status, cost factors and comfort. It can also serve to compare satisfaction results obtained with different user groups, in different service settings and in different countries. Finally, because the QUEST 2.0 is easier and shorter to complete than its original version, it can be used in research studies (e.g., postal surveys) that require rapid acquisition of satisfaction data.

The QUEST manual is organised as follows. Chapter 1 presents an overview of the development and psychometric testing of the original QUEST and the steps undertaken to construct the second version. Chapter 2 provides a complete description of the QUEST version 2.0 assessment tool and explains the QUEST form. Guidelines on how to administer, score and interpret the results are also provided. Chapter 3 highlights some of the psychometric properties of the QUEST 2.0 and invites the reader to consult the authors' recent publications on these findings. A list of publications on QUEST and the assessment materials are also included in this publication.

It is important to note how the terms "user" and "evaluator" are used throughout this manual. For reasons of clarity and consistency, the word "user" refers to the person who is being assessed; it refers to the consumer, the client, the patient or the respondent. The word "evaluator" refers to the professional who is either administering the QUEST or who is scoring and interpreting the results; it refers to the practitioner, the researcher, as well as the designer, manufacturer or vendor of assistive technology.

Development of the QUEST assessment tool

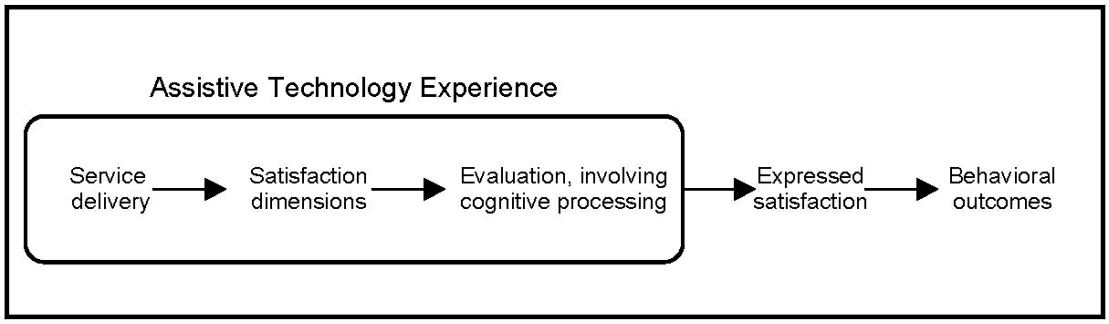
Theoretical background

Etymologically, the word "satisfy" means, "make enough". Satisfaction is a complicated multi-dimensional concept and to date there is little agreement about the factor structure of satisfaction measures. Although satisfaction can mean different things to different people, there is general agreement that satisfaction is an attitude about a service, a product, a service provider or an individual's health status.

From a psychological perspective, satisfaction is a subjective reaction, that is, a state of pleasantness, well being or gratification (Chaplin, 1985). According to Linder-Pelz (1982), satisfaction is a positive attitude; it is an affect that is the result of social psychological determinants including perceptions, evaluations and comparisons. Based on the theory and the research conducted in rehabilitation, Simon and Patrick (1997) define consumer satisfaction as a level of pleasantness, well being or gratification felt in reaction to a total specified experience or its components. In his comprehensive review article on patient satisfaction with rehabilitation services, Keith (1998) explains that satisfaction is comprised of affective components that reflect positive or negative feelings as well as cognitive components that are concerned with what is important and how it is evaluated. He maintains that if the factors that influence a patient's opinion cannot be identified then the satisfaction measures have little value. Furthermore, Keith (1998) argues that unless there is some uniformity in satisfaction questionnaires and instruments, it will not be possible to compare levels of satisfaction across settings and programs.

As shown in Figure 1, the relations between variables involved in the experience of assistive technology can be considered and represented linearly. The satisfaction is conceived as a reaction to the service delivery (dependent variable) and as a trigger to a subsequent action or behaviour (independent variable). In the case of assistive technology, as with other phenomenon, the construct is broken down into several dimensions that correspond to specific aspects of user satisfaction. The evaluation of these dimensions involves a cognitive process in which there is some degree of subjectivity involved. In this context, satisfaction as defined in the QUEST is based on a person's critical evaluation of specific characteristics of the technology. The person's expectations, perceptions, attitudes and personal values affect this assessment.

Figure 1: Satisfaction with assistive technology model



* Model of satisfaction inspired from Simon & Patrick (1997)

Construction of the original version

The methodology used to develop the original QUEST was described in detail in two recent publications (Demers, Weiss-Lambrou & Ska, 1996, 1997). This first version was divided into three parts. Part one consisted of 18 close-ended questions aimed at describing the context in which user assistive device satisfaction or dissatisfaction developed. In Part two, the user was asked to rate the degree of importance he or she attributes to 24 items associated with specific personal characteristics as well as features of the device and the environment. Using a 5-point scale, the degree of importance was

rated with a score ranging from 1 denoting *of no importance*, to a score of 5 indicating *very important*. Inasmuch as the QUEST was designed to assess a wide range of assistive technology devices, not all items were applicable to every user and every situation; the user was consequently allowed to score an item as *non-applicable*. In Part three of the QUEST, the user was asked to rate his or her satisfaction with the variables using a 5-point satisfaction scale, in which case a score of 1 signified *not satisfied at all* and 5 indicated *very satisfied*. For each item that was scored 3 (*more or less satisfied*), 2 (*not very satisfied*) or 1 (*not satisfied at all*), the user was asked to comment or explain the source(s) of dissatisfaction. Finally, the user was asked to rate his or her overall satisfaction with the device. It required approximately 45 minutes for the evaluator to administer the assessment in a face-to-face interview context.

The original QUEST was created in a "card-playing" format version only and the assessment materials were presented as a kit. These materials consisted of 24 playing cards (with each card representing a satisfaction item); an interactive assessment box for rating the variables and classifying the cards; a 5-point importance scale on one side of the box and a 5-point satisfaction scale on the reverse side; an instruction manual and a scoring sheet. QUEST was developed simultaneously in French and English, and a Dutch version translation was later constructed (Wessels, De Witte, Weiss-Lambrou, Demers, & Wijlhuizen, 1998).

Psychometric testing of the original version

Two studies were recently conducted concurrently to establish the psychometric properties of the original QUEST. The purpose of the first study was to perform **an international content validation study** of QUEST (Demers, Wessels, Weiss-Lambrou, Ska & De Witte, 1999). For this purpose, a specific questionnaire was developed to assess the value of the QUEST items and to critically analyse the administration and scoring procedures. This questionnaire was completed by an international group of 12 content experts from the United Stated, the Netherlands and Canada. These experts were provided with a QUEST kit and were given several months to apply and test the

instrument in a clinical or research context. At the test level, the findings revealed that QUEST had been adequately sampled in terms of embracing all the important facets of satisfaction with assistive technology. At the item level however, it was disclosed that changes needed to be made to the procedures used in administering QUEST and to the formulation of the satisfaction variables in order to ensure optimal content validity.

The aim of the second study was to determine at the item level, **the test-retest stability and the interrater reproducibility of QUEST** (Demers, Ska, Giroux & Weiss-Lambrou, 1999). A total of 139 subjects were administered the original QUEST on two occasions, 7 to 11 days apart. For a first cohort of subjects (n=85), the same rater administered both evaluations and for a second cohort (n=54), a different rater was involved. Reliability coefficients of the satisfaction ratings were found to be moderate to substantial for all the items with reference to stability and for 75% of the items with respect to reproducibility. The estimate coefficients were perceptibly weaker for the importance ratings whereas little variance in scores was observed. Based on the results of this study, the satisfaction scale was found to be reliable in terms of stability and reproducibility however the importance scale did not prove to be reliable for discriminating between and among users of assistive technology. From a validity perspective, these results confirmed that QUEST had adequate content coverage because it embraced those aspects of satisfaction that were considered important to the users. However in terms of reliability, the obtained coefficients did not support the usefulness of rating the importance of each of the QUEST items. More than half the items did not generate a moderate or higher level of agreement. The significance of this finding was that the task of scoring the importance of the items would not be included in the subsequent version of QUEST.

Creation of the QUEST 2.0

One of the goals in test construction is to develop a test of minimal length that will yield scores with the desired degree of reliability and validity for the intended uses. Based on the findings of the previous two studies (Demers, Ska et al., 1999; Demers, Wessels et

al., 1999), an item analysis of 24 items comprising the original QUEST was conducted. These results are reported in an article that will soon be published in the journal *Assistive Technology* (Demers, Weiss-Lambrou & Ska, in press). In order to select a subset of items that would demonstrate optimal measurement properties, several criteria were used: general acceptability, content validity, criterion validity, contribution to internal consistency, test-retest stability and instrument sensitivity. The items that ranked best in terms of these measurement properties were then submitted to factorial analysis. The results of this factor analysis revealed that the underlying structure of satisfaction with assistive technology consists of two dimensions: one related to the assistive technology **DEVICE** (eight items) and one associated with the assistive technology **SERVICES** (four items). This finding was cross validated in a Dutch sample of 253 device user subjects and an identical structure was obtained thereby strongly supporting the stability of the QUEST satisfaction model (Figure 2).

Figue 2: QUEST satisfaction model

Quebec User Evaluation of Satisfaction with assistive Technology

QUEST (Version 2.0)

Technology device: _____

User name: _____

Date of assessment :_____

The purpose of the **QUEST** questionnaire is to evaluate how satisfied you are with your assistive device and the related services you experienced. The questionnaire consists of 12 satisfaction items.

- For each of the 12 items, rate your satisfaction with your assistive device and the related services you experienced by using the following scale of 1 to 5.

1	2	3	4	5
not satisfied at all	not very satisfied	more or less satisfied	quite satisfied	very satisfied

- Please circle or mark the **one number** that best describes your degree of satisfaction with each of the 12 items.
- D**o not** leave any question unanswered.
- For any item that you were not "very satisfied", please comment in the section ***comments***.

Thank you for completing the QUEST questionnaire.

1	2	3	4	5
not satisfied at all	not very satisfied	more or less satisfied	quite satisfied	very satisfied

ASSISTIVE DEVICE ***How satisfied are you with,***	
1. the **dimensions** (size, height, length, width) of your assistive device? *Comments*:	1 2 3 4 5
2. the **weight** of your assistive device? *Comments*:	1 2 3 4 5
8. how **effective** your assistive device is (the degree to which your device meets your needs)? *Comments*:	1 2 3 4 5

1	2	3	4	5
not satisfied at all	not very satisfied	more or less satisfied	quite satisfied	very satisfied

SERVICES ***How satisfied are you with,***	
9. the **service delivery** program (procedures, length of time) in which you obtained your assistive device? *Comments*:	1 2 3 4 5
12. the **follow-up services** (continuing support services) received for your assistive device? *Comments*:	1 2 3 4 5

RESISTANCE TO ILLNESS INDEX QUESTIONNAIRE

The standardized self-administered Resistance to Illness Index (Indice de Resistencia a la Enfermedad – IRE) is an original Spanish questionnaire, which attemps to operationalize the personal and social resources increasing or decreasing the resistance to illness. Its conceptualization underlines a notion of human life based on two basic dimensions: "anguish" and "illusion". The combination of the two dimensions –summarized in a global index- would represent the variable individualized judgment and answer to face similar vital events or objective state of health or illness. The 20 items of the IRE questionnaire are grouped in two subscales representing the two defined dimensions: "anguish" subscale (10-items considered with negative sense) and "illusion" subscale (10-items considered with positive sense). The two subscales can be combined to outcome a total score (=global score of resistance to illness). Every item has a Likert type scaling (ranging from 0 to 4), so the categories of answer to the items cover 5 levels (0= not at all , 1= slightly , 2= moderately , 3= strongly, 4= very strongly).

Abbreviated Name: IRE
Author(s): Juan Antonio Fernández López
Purpose: To conceptualize and operationalize the personal and social resources increasing or decreasing the resistance to illness
Population: Adult
Age Range : 18 and over
Type of Instrument: Coping
Mode of Administration:

Rater:	Self -administered
Time required:	5 minutes
Response Options:	Likert scale
Scoring:	Global score: Minimum score: -40 / Maximum score: +40 "Illusion / Anguish" ratio
Score Direction:	Higher scores show better QoL

Number of Items: 20
Original Language: Spanish
Existing Translations : English, German

Copyright: Fernández-López JA, Spain 2001

Contact for information and permission to use:

Juan Antonio Fernández López
University of Orviedo
La Vega de Rosia
33160 – Asturias Spain
Phone : +34 985 76 66 14
Fax : +34 985 76 62 93
Email: jflopez@correo.uniovi.es
jaflopez@wanadoo.es

Dimensions covered by the questionnaire :

- Anguish subscale (10 items)
- Illusion subscale (10 items)

Key References:

1. Fernández-López JA, Fernández-Fidalgo M:. Resistance to Illness Index (IRE questionnaire). Quality of Life Newsletter 2004;32:17-19. 2.

2. J.A Fernández-López et al. Testing the Measurement Properties of the English Version of the Resistance to Illness Index (IRE Questionnaire) Quality of Life Newsletter 2005;35:6-8.

THEORETIC MODEL OF THE "RESISTANCE TO ILLNESS INDEX" (IRE^R QUESTIONNAIRE)

So far the Health Related Quality of Life (HRQoL) research has been developed with an important concession: the renunciation, for practical reasons, to study in detail the intrapsychic and interpersonal processes of overcoming and resistance to illness [1].
The standardized psychometric approach "**Resistance to Illness Index**" attempts to conceptualize and operationalize the personal and social resources increasing or decreasing the resistance to illness. Basically we argue that this approach provides a representation of sociological, interpersonal dimensions in addition to intrapsyhic resources.
This conceptualization underlines a notion of human life and its components proposed most convincingly by the Spanish philosopher José Ortega y Gasset (1883-1955), i.e. in life the essential is the future [2-4]. According to this idea each human being first imagines what he would like his life to be. As future is something that **enthuses us** and at the same time **anguishes us**, **we emphasize the "anguish-illusion" binomial as an important determinant of HRQoL and of coping skills**. The Spanish concept of "illusion" has not negative sense as commonly in the most languages but positive sense, something similar to what we could convey into English as "enthusiasm"or "hope"[5-6].
Thus both dimensions "anguish-illusion" appear faced one to another, as in a pair of scales, where one dimension determines the level of the other one. Of course, through life, in different ages, each dimension changes and so may have an unequal weighting. However, as the relationship between the two basic dimensions is a dialectic connection, such dialectic will appear always and only will vary the point on the line of this relationship. Sometimes this point will be closer to a pole of the scale and another times it will be closer to the opposite pole.
Thus the combination of two basic dimensions –summarized in a **global index**- would represent the variable individualized answer in the face of similar vital events or objective states of health or illness. We assume that the higher value in the global index the higher overcoming capacity or resistance to illness.
The standardized self-administered IRE^R questionnaire represents an approach towards assessing resistance to illness in healthy and chronically ill people. In its methodologic development the goal was essentially pragmatic: to design a short instrument easily understandable, feasible in setting and with a clear prognosis pointing. Likewise, the instrument should be used in different types of study, namely: a) epidemiological studies, b) clinical studies dealing with the effects of individual overcoming capacity on therapeutic measures applied to acute and chronically ill patients, and c) in prevention and rehabilitation programmes, looking into the effects of individual resistance to illness on health or on the disease course.
Concerning to the test-testatistical properties the following information is briefly summarized. Applying exploratory Principal Components Analysis we usually observe two uni-dimensional factors defining two scales, as conceptually is defined. Of course, the replication of the factorial structure to some extent depends on the composition of the group under study. Moreover we suppose a one-dimensional latent structure of the whole construct of "resistance to illness" and therefore we recommend to evaluate the results specifically according to the scores of the global index.
The reliability of the scales (Cronbach`s alpha) is higher than 0.80 for single scales and for the total questionnaire, and its discriminant validity including both chronically ill and healthy people, different age and gender groups has been tested (Observations not yet published).

Structure of the IRE^R Questionnaire

It is composed of a general, non specific part, that measures two basic coping related dimensions: "anguish-illusion" by means of 20 Likert-scaled ítems. In addition, a sociodemographic general module (8 ítems) and one global question have been included (item 21). Applications of this measure require some 5 minutes, and in specific target groups (e.g. impaired sight or disabled condition), the test can be applied as an interview as well. The test is intented for adult people excluding children. We did not observe high non-response rates or significant differences in response according to age, gender or socioeconomic status. Thus, the test can be applied widely among chronically ill and healthy people.

The 20 ítems of the IRE^R questionnaire are grouped in two subscales representing the two defined basic dimensions: **anguish subscale** (10 ítems) and **illusion subscale** (10 ítems). The two subscales can be combined to outcome a total score (= **global index** of resistance to illness). Every item in the IRE^R questionnaire has a Likert type scaling (ranging from 0 to 4), so the categories of answers to the ítems cover 5 levels (0= not at all, 1= slightly, 2= moderately, 3= strongly, 4= very strongly).

The 'anguish' subscale is composed of 10 ítems considered with a negative sense (ítems 1-10, marked with an asterisk in the questionnaire) and the 'illusion' subscale covers 10 ítems considered with a positive sense (ítems 11-20). Adding the scores from the two subscales the "resistance to illness index" is produced.

Analysis of the IRE^R questionnaire

Four modes are proposed to analyze the scores collected with the IRE^R questionnaire:

1º) To reduce the scores collected with all ítems to a **sum score**. The ítems` raw values are added considering the negative value of ítems 1-10 (ranging sum score from 0 to –40) and the positive value of the ítems 11-20 (ranging sum score from 0 to +40). So the sum score of both subscales (=global index) ranges between -40 and +40. Then -40 means the minimum resistance capacity to face up to illness, and +40 means the maximum possible capacity. The 0 value is the cut point.

In such a manner we can discriminate among subjects according to level of resistance to illness as following:

- Sum scores lower –14 = Very low resistance to illness
- Sum scores between –14 and 0 = Low resistance to illness
- Sum scores between 0 and 7 = Minimal resistance to illness (limit zone)
- Sum scores between 7 and 14 = High resistance to illness
- Sum scores higher 14 = Very high resistance to illness

This mode is the simplest way to setting application of the questionnaire. A quick manual analysis of the questionnaire is possible and, furthermore is the incorporation of the results to clinical decision process.

2º) Calculation of the **"illusion/anguish"** ***ratio***. This calculation is based on the previous one. We propose to construct a ratio of the two scores anguish and illusion. To compute the ratio the score illusion is put in the nominator and the score anguish in the denominator without considering their sign. By applying this algorithm a standardized summary of the model is defined where a threshold of 1.0 discriminates between a high risk group (values <1.0) and a group at lower or no risk (values >1.0).

3º) To reduce the **sub-scale score and global index** to a mean value between 0 and 4 recoding the ítems with a negative sense (ítems 1-10) in the following way: 0=4, 1=3, 2=2, 3=1, 4=0. In this case the mean score can be obtained by dividing the subscale's total score into the number of sub-scale ítems. The 0 value means the minimum resistance capacity, and the 4 value means the maximum possible resistance.

4º) Calculation of scores of every subscale and global index **transformed to 100**. The mean values of the subscales and the global index are transformed to values from 0 to 100, where 0 = minimum value, 100= maximum value of resistance.

Formulae and examples for calculating subscale sum scores

1) **Sum score** =Sum of sub-scale ítems

Example:
Anguish sum score (negative)=Sum of ítems 1-10 x (–1)
(range: from 0 to – 40)
Illusion sum score (positive) =Sum of ítems 11-20
(range: from 0 to +40)
Index sum = Negative anguish sum score + Positive illusion sum score

(range: from –40 to +40)

2) ***Ratio* "illusion/anguish"** = $\frac{\text{Sum of ítems } 11,12,13,14,15,16,17,18,19,20}{\text{Sum of ítems } 1,\ 2,\ 3,\ 4,\ 5,\ 6,\ 7,\ 8,\ 9,\ 10}$

3) **Sub-scale score** = $\frac{\text{Sum of sub-scale ítems}}{\text{Number of sub-scale ítems}}$

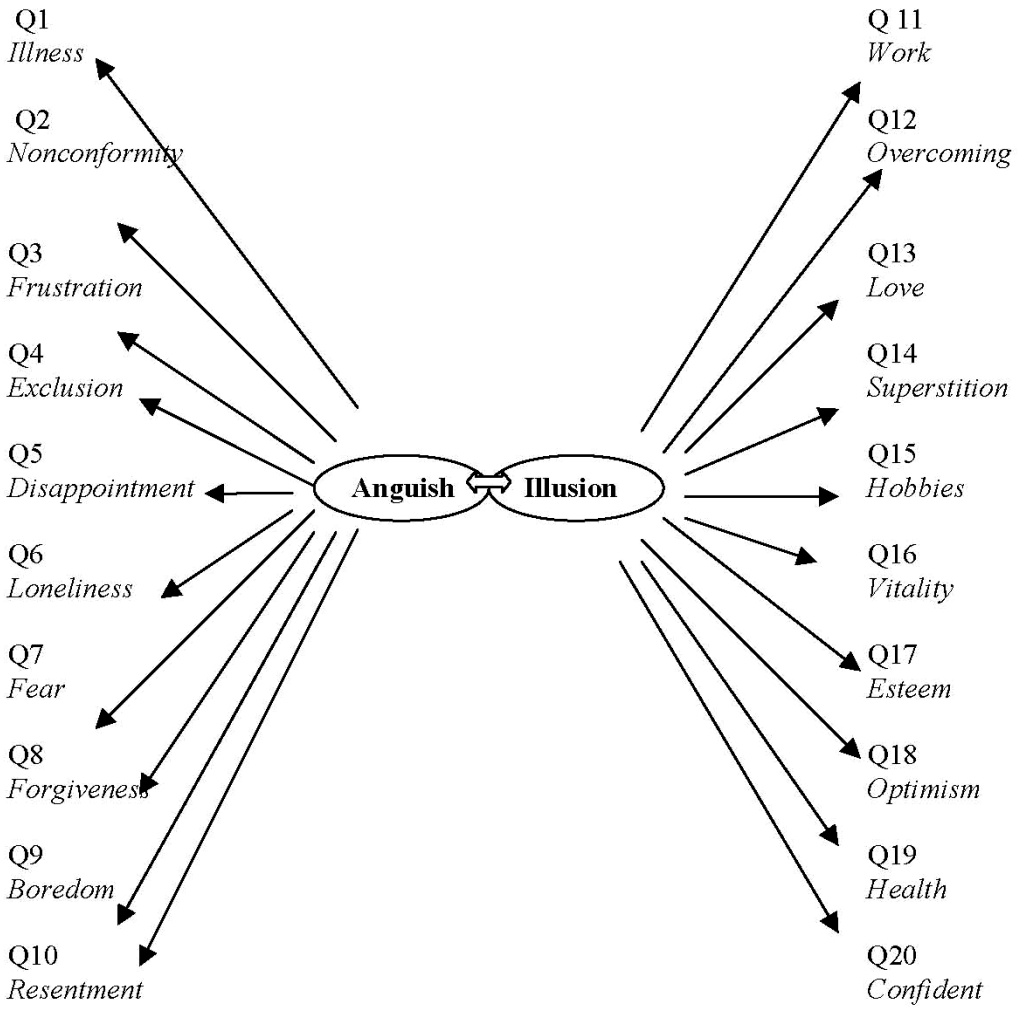
Example:
Anguish sub-scale score = $\frac{\text{Sum of ítems 1-10 } \mathbf{recoded}}{10}$
(range from 0 to 4)
Illusion sub-scale score = $\frac{\text{Sum of ítems 11-20}}{10}$
(range from 0 to 4)
Index score = $\frac{\text{Sum of all ítems}}{20}$
(range from 0 to 4)

4) **Sub-scales transformed to 100**= $\frac{\text{Sub-scale score – lowest possible score}}{\text{Possible range of raw score}} \times 100$

The calculations described here may be found in the SPSS file " ire_sum.spss" or "ire_mean.sps" on the disc for data analysis.

CHART 1. NOMINATED STRUCTURE OF THE RESISTANCE TO ILLNESS INDEX (IRE QUESTIONNAIRE)©

DIAGRAM OF FLOWS



RESISTANCE TO ILLNESS INDEX (IRE^{R} QUESTIONNAIRE)

Code Nº:

Dear patient:

With the following questions we are trying to know the degree of your resistance to illness. This is an important information for improving the therapy for you and others patients. Please, make sure you answer every question. Choose only one answer and mark it with a cross (X).

Of course, your answers will be confidentialy treated.

Thank you for your collaboration!

First of all some questions about your social situation:

1. Name: 2. Year from birth: 19___

3. Sex : Male ☐
Female ☐

4. Marital status: Married ☐
Single ☐
Divorce ☐
Widow(er) ☐

5. Do you live together? Yes ☐
No ☐

6. Level of studies achieved : None ☐
Primary studies ☐
Secondary studies ☐
Professional studies ☐
University studies ☐

7. Labor situation : Manual worker on active service ☐
No manual worker on active service ☐
Unemployed ☐
Housewife ☐
Retired ☐
Student ☐
Others:_____

8. Clinic diagnosis: Healthy ☐
Cancer ☐
Cardiopatie ☐
Depression ☐
Others: _____

Date:

Q1. Are you afraid of the illness to stop you from living your future life normally? (*)

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q2. Is it difficult for you to accept the everyday difficulties? (*)

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q3. Have you got the impression of not getting what you want? (*)

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q4. Do you feel yourself misunderstood or not taken seriously by the others? (*)

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q5. Are you upset by being unable to achieve what you want? (*)

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q6. Do you miss anybody and feel alone? (*)

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q7. Are you afraid of the future? (*)

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q8. Do you get angry with yourself because of the mistakes you make? (*)

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q9. Do you feel bored? (*)

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q10. Do you feel bitter due to suffered disappointments? (*)

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q11. Do you feel enthusiastic about your occupations or works?

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q12. Do you feel necessary to better yourself day after day?

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q13. Do you feel really involved with someone?

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q14. Do you think that your future depends on what you do?

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q15. Do you keep any helpful hobby alive?

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q16. Do you feel active and full of energy?

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q17. Do you think that your life and effort are necessary?

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q18. Are you capable of getting glad about anything?

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q19. Are you confident that your health will let you live your future life normally?

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q20. Do you feel able to overcome future difficulties?

not at all	slightly	moderately	strongly	very strongly
0	1	2	3	4

Q21. Generally speaking, would you say that your present life coincides with what you expected?

It is much worse	It is a bit worse	It is as expected	It is a bit better	It is much better
0	1	2	3	4

ÍNDICE DE RESISTENCIA A LA ENFERMEDAD (IRE)

Estimado paciente:

Con las siguientes preguntas pretendemos conocer su estado de ánimo y su capacidad de enfronte o resistencia a la enfermedad. Esta información es útil tanto para su tratamiento como para el de otras personas.

Por favor, asegúrese que contesta **todas** las preguntas.

Elija **solamente una respuesta** y márquela con una cruz (X).

Un ejemplo:	Nada, en absoluto	Un poco	Modera-damente	Mucho	Muchísimo
¿En qué medida se nota activo/a y lleno/a de energía?	☐	☐	☐	☒	☐

Por supuesto, sus respuestas serán tratadas **confidencialmente.**

En primer lugar algunas cuestiones acerca de su situación:

1. Año de nacimiento: 19___	2. Sexo: Hombre ☐ Mujer ☐
3. Estado Civil: Casado ☐ Soltero ☐ Divorciado ☐ Viudo ☐	4. ¿Vive en pareja?: Sí ☐ No ☐
5. Nivel de estudios que alcanzó: Ninguno ☐ Primarios ☐ Bachillerato/FP ☐ Título grado medio ☐ Título universitario ☐	6. Situación laboral: Trabajador por cuenta ajena ☐ Parado ☐ Ama de casa ☐ Jubilado ☐ Estudiante Autónomo ☐ Otros, especifíquese:_____
Cuestionario rellenado el: _____	SITIO PARA PEGATINA O

Por favor, marque <u>sólo una</u> respuesta por cada pregunta.
Seleccione la que mejor se adapte a su sentimiento personal

(A)

¿En qué medida...	Nada, en absoluto	Un poco	Modera-damente	Mucho	Muchísimo
	0	1	2	3	4
1. ....teme que la enfermedad le impida hacer su	☐	☐	☐	☐	☐
2. ... le cuesta aceptar las dificultades que la vida le	☐	☐	☐	☐	☐
3. ... tiene la impresión de que no consigue lo que quiere?	☐	☐	☐	☐	☐
4. ... se siente incomprendido/a o poco tomado/a en	☐	☐	☐	☐	☐
5. ... le afecta no poder lograr lo que quiere?	☐	☐	☐	☐	☐
6. ... echa de menos a alguien y por eso se siente solo/a?	☐	☐	☐	☐	☐
7. ... siente miedo ante el futuro?	☐	☐	☐	☐	☐
8. ... se enfada consigo mismo/a por los errores que	☐	☐	☐	☐	☐
9. . ... se siente aburrido/a y sin gracia?	☐	☐	☐	☐	☐
10. **... está resentido/a por los desengaños sufridos?**	☐	☐	☐	☐	☐

...

⇒

Por favor, marque <u>sólo una</u> respuesta por cada pregunta.
Seleccione la que mejor se adapte a su sentimiento personal
(B)

¿En qué medida...	Nada, en absoluto	Un poco	Modera-damente	Mucho	Muchísimo
	0	1	2	3	4
11. . ... está ilusionado/a con sus ocupaciones o trabajo?	☐	☐	☐	☐	☐
12. ... siente la necesidad de superarse cada día un poco más?	☐	☐	☐	☐	☐
13. ... se siente verdaderamente unido/a a alguna persona?	☐	☐	☐	☐	☐
14. ... cree que su futuro depende de lo que Ud. haga?	☐	☐	☐	☐	☐
15. ... mantiene viva alguna afición que le sirve de ayuda?	☐	☐	☐	☐	☐
16. ... se nota activo/a y lleno/a de energía?	☐	☐	☐	☐	☐
17. ... siente que su vida y su esfuerzo son necesarios para alguien?	☐	☐	☐	☐	☐
18. ... es capaz de alegrarse por poca cosa?	☐	☐	☐	☐	☐
19. ... confía en que la salud le permita llevar con normalidad su vida futura?	☐	☐	☐	☐	☐
20. ... se siente capaz de superar las dificultades que le sobrevengan?	☐	☐	☐	☐	☐

...

⇒

Finalmente una pregunta de carácter global.
Marque sólo <u>una</u> respuesta.

	Es mucho	Es algo peor	Es como esperaba	Es algo mejor	Es mucho mejor
	-2	-1	0	1	2
21. ¿En general, en qué medida diría que su vida actual coincide con lo que Usted esperaba de ella?	☐	☐	☐	☐	☐

¡¡ Muchas gracias por su colaboración !!

<u>Nota para el análisis</u>:

(A): Preguntas 1-10 = Suma de puntos x (-1)= Valor Negativo. Rango: 0 a – 40.
(B): Preguntas 11-20= Suma de puntos x (1) = Valor Positivo. Rango : 0 a + 40.

Índice de Resistencia a la Enfermedad = Valor A + Valor B.

<u>Valores de referencia</u>:

- **de –40 a –14 puntos = Muy baja resistencia**
- **de –14 a 0 puntos = Baja resistencia**
- **de 0 a 7 puntos = Resistencia mínima (zona límite)**
- **de 7 a 14 puntos = Alta resistencia**
- **de 14 a 40 puntos = Muy alta resistencia**

SAT-16

The SAT-16 is a questionnaire aiming to measure patient satisfaction with respect to the perceived quality of the main aspects of the care actually received during on admission staying in a rehabilitation inpatient unit. The questionnaire is suitable for clinical and research applications in the field of a consumer satisfaction survey for evaluation and improvement of quality in inpatient medical rehabilitation.

Abbreviated Name: SAT-16
Author(s): Franchignoni F, Ottonello M, Benevolo E, Tesio L.
Purpose: To measure patient satisfaction with respect to the perceived quality of the main aspects of the care actually received during stay in a rehabilitation inpatient unit
Population: Adult
Age Range : 18+ years
Type of Instrument: Satisfaction
Mode of Administration:

Rater:	Self -administered
Time required:	5 minutes
Response Options:	Likert scale
Scoring:	Global score: Minimum score: 16 / Maximum score: 80 Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 16
Original Language: Italian

Copyright:

Contact for information and permission to use:

Franco Franchignoni, MD
Fondazione Salvatore Maugeri
Unit of Occupational Rehabilitation and Ergonomics,
Rehabilitation Institute of Veruno, Italy
Email: ffranchignoni@fsm.it

Dimensions covered by the questionnaire :

- Medical care (3 items)
- Physiotherapist care (3 items)
- Nursing care (3 items)
- Food and catering (3 items)
- Physical environment and support services (4 items)

Key References:

1. Franchignoni F, Benevolo E, Ottonello M, Tesio L. Validazione di una scala di soddisfazione del paziente in degenza riabilitativa. Minerva Med 1997; 88:237-44.

Background: A new scale is presented, measuring patients' satisfaction with respect to the quality of care during stay in a rehabilitation unit. The questionnaire is self-administered and anonymous, and it includes 15 items, scored 1 to 4. The cumulative score may thus range 15-60; the higher the score, the higher the patient's satisfaction. Materials and Methods: The instrument was proposed to 175 disabled patients, admitted to a free-standing Centre for rehabilitation following neurological or orthopedic impairments. Results: One hundred and forty questionnaires were completed. Of these, 131 could be analyzed. The mean score was > 3 in every item. Factor analysis disclosed that the questionnaire comprises 5 factors, which may be defined as "medical care", "physiotherapy", "nursing care", "food" and "physical environment and facilities". A satisfactory internal consistency of the items was found (item-remainder correlations > 0.5, Cronbach alpha > 0.9). This suggests that the scale is sufficiently unidimensional to permit cumulative summing of the item scores. Conclusions: The results suggest the content and construct validity of the scale. The questionnaire thus merits further psychometric investigation.

2. Franchignoni F, Benevolo E, Ottonello M, Tesio L, Battaglia MA. [Validity and reliability of a new questionnaire on patient satisfaction in rehabilitative therapy] Validità ed affidabilità di un nuovo questionario sulla soddisfazione del paziente in degenza riabilitativa. Minerva Med 1998; 89:57-64.

Background: The aim of this study was to examine some psychometric properties of a new questionnaire measuring patients' satisfaction with respect to the quality of care during stay in a rehabilitation unit. The instrument (called SAT-16) is composed of 16 four-level items and 2 open-ended questions. The construct validity of the 16-item section was already demonstrated in a previous study based on factorial analysis. In this study the concurrent validity, further aspects of the construct validity and test-retest reliability were analyzed. Methods: The SAT-16 was administered to 339 inpatients, admitted consecutively to a Rehabilitation Center. Results: 262 questionnaires (77%) were returned, of which 221 with all items filled in. The SAT-16 correlated well with two other measures of satisfaction (CSQ-8 and global satisfaction regarding the hospital stay). The answers to two open-ended questions came out to be consistent with those to the 16 closed-ended questions. The high values for the indices of test-retest reliability (ICC and kappa) are evidence of the stability of the scores in two repeated administrations. Conclusions: The SAT-16 was found to be provided with good psychometric characteristics. It can be proposed as a valid instrument for use in clinical practice for the continuous quality improvement of inpatient medical rehabilitation programmes.

3. Franchignoni F, Ottonello M, Benevolo E, Tesio L. Satisfaction with hospital rehabilitation: is it related to life satisfaction, functional status, age or education? J Rehabil Med 2002; 34:105-108.

Satisfaction with care, functional and cognitive status, life satisfaction, anxiety, and sociodemographic variables were correlated in 55 in-patients admitted to a rehabilitation unit after hip or knee surgery. The study aimed at investigating whether, as an index of care quality, patient satisfaction can be considered as a distinct domain or instead is subsidiary to other patient characteristics. Patient satisfaction with rehabilitation care was measured through a questionnaire, SAT-16. The SAT-16 scores were moderately correlated with a short form of the Life Satisfaction Index (LSI-11: rs = 0.41, p = 0.001), but did not correlate with either the Functional Independence Measure (FIM), the STAI form X (the Spielberger State-Trait Anxiety Inventory), age or educational level. According to the "discrepancy model", the fair degree of correlation between SAT-16 and LSI-11 could be explained by connecting both expressions of satisfaction with personal background expectations and their perceived degree of fulfilment. The results confirm, also for rehabilitation care, that patient satisfaction should be considered as a valuable specific outcome, independent of most of the patient characteristics investigated (functional and cognitive status, anxiety, age, and education).

SAT-16 QUESTIONNAIRE

1. Origin

The instrument is original. The starting point for its development was a questionnaire for patient satisfaction in general hospitals found within an Italian Decree on policies of the public health services (Gazz. Uff. n.125 del 31.5.1995 - "Schema generale di riferimento della Carta dei Servizi pubblici sanitari"). A pre-testing phase included a content validation of the questionnaire by a committee of experts.

2. Purpose

The SAT-16 is a questionnaire aiming to measure patient satisfaction with respect to the perceived quality of the main aspects of the care actually received during stay in a rehabilitation inpatient unit.

3. Population

The instrument has been validated in two patient samples (175 + 262 subjects with disabilities, consecutively admitted to a free-standing rehabilitation centre following neurological or orthopedic impairments).
All subjects scored > 24 on the Mini Mental State Examination (i.e. above the acknowledged threshold for mental deterioration), indicating that they were cognitively "normal".

4. Administration

Rater - The questionnaire is self-administered. The patient receives it three to four days before discharge and after filling it out places it in a box in anonymous fashion.
No specific *training* is needed for the person in charge of collection and scoring of the ordinal data.
Time required for compilation: less than five minutes
Scoring: The SAT-16 includes 16 items using a five-point satisfaction rating scale (1- very dissatisfied; 2- quite dissatisfied; 3- neither satisfied nor dissatisfied; 4- rather satisfied; 5- very satisfied). The cumulative score is obtained by summing the scores of the 16 items: the higher the score, the higher the patient's satisfaction.

5. Description

The instrument is composed of two sections:
i) 16 closed-ended questions (rated according to a five-point evaluation rating scale, see Scoring) that analyse five domains of the patient's satisfaction: 1-3) care, attitudes and explanations of medical, nursing and therapist staff, respectively (3 items for each dimension); 4) food and catering characteristics (3 items); 5) physical environment and support services (cleanliness, comfort and privacy, time-table of ward rounds and therapies) (4 items);
ii) 3 open-ended questions about positive and negative aspects of the hospital stay and client's suggestions for improving the hospital services.
All the questions refer to the perceived quality of service of a specific episode of care (a hospital stay in a rehabilitation unit).

6. Coverage

The questionnaire is suitable for clinical and research applications in the field of a consumer satisfaction survey for evaluation and improvement of quality in inpatient medical rehabilitation.

7. Reliability

Internal consistency

Item-remainder correlations: Pearson coefficients ranging 0.50 - 0.70
Cronbach's alpha: 0.90
Kaiser-Meyer-Olkin measure of sample adequacy: 0.80

Test-retest reliability

Cohen's kappa: single item 0.48 - 0.84
ICC (2,1): cumulative score 0.77, single item 0.62 - 0.89
Standard Error of Measurement: 0.12 - 0.38

8. Validity

Concurrent validity

The SAT-16 correlated well with two other measures of satisfaction: the CSQ-8 ($r= 0.54$, $p=0.002$) and an index of global satisfaction regarding the hospital stay ($r= 0.79$, $p=0.0001$)

Construct validity

Factor analysis disclosed that the questionnaire comprises five factors, which may be defined as "medical care", "physiotherapist care", "nursing care", "food and catering" and "physical environment and support services"
Furthermore, the answers to two open-ended questions (respectively, positive and negative aspects of the received care), regarding the five domains of satisfaction disclosed by the factor analysis, came out to be consistent with those to the 16 closed-ended questions.

9. Responsiveness

The comparison between the answers in two time periods in the interval between which an improvement in some hospital services could have hypothetically occurred showed a statistically significant increase of the scores for the respective items.

10. Strengths

The SAT-16 exhibits evidence of robust psychometric properties, such as an adequate estimate of reliability and validity.
The self-reported questionnaire allows standardization and anonymity, avoids the response bias due to the interviewer, has a low cost and needs no specialized personnel for its management.
The choice of a 5-level ordinal scale permits a sufficient differentiation of levels of satisfaction, two of which are positive, two negative, and one intermediate.

11. Weaknesses

The raw score obtained by summing responses are ordinal in nature, which precludes its use in parametric statistical comparison.
The open-ended questions need to be evaluated by an expert in quality assessment of health care (usually a registered nurse or a physician).
The SAT-16 has not been used for gathering data from patients suffering from cognitive or expression/comprension deficits. The proxy ratings have not been tested.

12. Suggestions

The SAT-16 structure needs further refinement and validation (including the deletion of 1 or 2 items - eg on food - and the addition of some other to cover more satisfaction sub-domains).

Bibliography

a) Franchignoni F, Benevolo E, Ottonello M, Tesio L. Validazione di una scala di soddisfazione del paziente in degenza riabilitativa. Minerva Med 1997; 88: 237-244 (in Italian with abstract in English)
b) Franchignoni F, Benevolo E, Ottonello M, Tesio L, Battaglia MA. Validità ed affidabilità di un nuovo questionario sulla soddisfazione del paziente in degenza riabilitativa. Minerva Med 1998; 89: 57-64 (in Italian with abstract in English)
c) Franchignoni F, Ottonello M, Benevolo E. Un nuovo questionario per la valutazione della soddisfazione del paziente in degenza riabilitativa. Giorn Ital Med Riabil 1998; 12:79-81 (in Italian)
d) Franchignoni F, Ottonello M, Benevolo E, Tesio L. Satisfaction with hospital rehabilitation: is it related to life satisfaction, functional status, age or education? J Rehabil Med. 2002 May;34(3):105-8.

FONDAZIONE SALVATORE MAUGERI - CENTRO MEDICO DI VERUNO

QUESTIONARIO PER I DEGENTI ETA': ……. Anni; **SESSO**: maschile ❑ femminile ❑; **SCOLARITA'** (anni di studio):…….

La preghiamo di rispondere alle seguenti domande per aiutarci a migliorare l'assistenza nel nostro Istituto. Sbarri il quadrato **X** *corrispondente al grado di soddisfazione che meglio esprime la Sua opinione. Le risposte rimarranno anonime anche per il personale di reparto. Se crede può farsi aiutare dai Suoi familiari nel compilare questa scheda. Le saremmo grati se segnalerà in dettaglio, negli appositi spazi sul retro del foglio, gli aspetti positivi e negativi del Suo ricovero.*

Che cosa pensa rispetto a :	**MOLTO SODDISFATTO**	**ABBASTANZA SODDISFATTO**	**NE' SODDISFATTO**	**ABBASTANZA INSODDISFATTO**	**MOLTO INSODDISFATTO**
Assistenza medica	❑	❑	❑	❑	❑
Assistenza infermieristica	❑	❑	❑	❑	❑
Assistenza fisioterapica	❑	❑	❑	❑	❑
Informazioni ricevute dai medici su diagnosi, decorso e cure	❑	❑	❑	❑	❑
Informazioni ricevute da caposala e infermieri professionali	❑	❑	❑	❑	❑
Informazioni ricevute da fisioterapisti	❑	❑	❑	❑	❑
Relazioni umane con il personale medico	❑	❑	❑	❑	❑
Relazioni umane con il personale infermieristico	❑	❑	❑	❑	❑
Relazioni umane con i fisioterapisti	❑	❑	❑	❑	❑
Pulizia e igiene della stanza e del reparto	❑	❑	❑	❑	❑
Ambiente e comfort (arredamento, tranquillità, ecc.)	❑	❑	❑	❑	❑
Orario e organizzazione delle visite di reparto	❑	❑	❑	❑	❑
Cibo: Qualità	❑	❑	❑	❑	❑
Cibo: Quantità	❑	❑	❑	❑	❑
Cibo: Orario pasti	❑	❑	❑	❑	❑
Disponibilità di servizi accessori (telefoni, gettoni, bibite, ecc.)	❑	❑	❑	❑	❑
Grado di soddisfazione globale del Suo ricovero	❑	❑	❑	❑	❑

÷ utilizzi anche la facciata posteriore

SEGNALI PER FAVORE le sue osservazioni e i suoi suggerimenti per i vari aspetti del suo ricovero.

ASPETTI POSITIVI_____

ASPETTI NEGATIVI_____

SUGGERIMENTI_____

FONDAZIONE SALVATORE MAUGERI CENTRO MEDICO DI VERUNO

SAT-16 QUESTIONNAIRE AGE: ……. years; SEX: male ❑ female ❑; EDUCATION (years of study): …….

Kindly answer the following questions which will aid us in improving the care in our Institute. Put an **X** *in the box alongside the expression which best expresses your opinion. The answer will remain anonymous and will not be seen by the ward staff. If you wish you may ask a family member to help you in filling out the questionnaire. We would be grateful if you could indicate in detail, in the appropriate spaces on the back of this sheet, the positive and negative aspects of your hospital stay and your suggestions for improving our services.*

What do you think about :	VERY SATISFIED	QUITE SATISFIED	NEITHER SATISFIED NOR DISSATISFIED	QUITE DISSATISFIED	VERY DISSATISFIED
1. Care (technical skills: thoroughness, carefulness, competence) by the doctors	❑	❑	❑	❑	❑
2. Care by the nurses	❑	❑	❑	❑	❑
3. Care by the physiotherapists	❑	❑	❑	❑	❑
4. Doctors' explanations about diagnosis and treatment	❑	❑	❑	❑	❑
5. Nurses' explanations about treatment	❑	❑	❑	❑	❑
6. Physiotherapists' explanations about treatment	❑	❑	❑	❑	❑
7. Human relations (personal manner: courtesy, respect, sensitivity, etc.) with the medical staff	❑	❑	❑	❑	❑
8. Human relations with the nursing staff	❑	❑	❑	❑	❑
9. Human relations with the physiotherapists	❑	❑	❑	❑	❑
10. Cleanliness of the room and ward	❑	❑	❑	❑	❑
11. Hospital environment and living conditions (comfort, calm, privacy, etc.)	❑	❑	❑	❑	❑
12. Timetable of the ward rounds, and therapeutic interventions/ treatments	❑	❑	❑	❑	❑
13. Food quality	❑	❑	❑	❑	❑
14. Food quantity	❑	❑	❑	❑	❑
15. Meal hours	❑	❑	❑	❑	❑
16. Availability of accessory services (telephones, bar, etc)	❑	❑	❑	❑	❑

÷ please turn over

PLEASE, indicate your comments and suggestions about your hospital stay:

POSITIVE ASPECTS

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NEGATIVE ASPECTS

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SUGGESTIONS

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SATISFACTION PROFILE

The Satisfaction Profile (SAT-P) is a questionnaire providing a satisfaction profile. Satisfaction can be defined as the cognitive product of the comparison between ideal life and reality, and can therefore be quantitatively measured. The SAT-P consists of 32 items which refer to daily life. The patient rates his satisfaction with each of them, independently of his objective health status, on a 10-cm horizontal visual analog scale (score range: 0-100): the higher the score, the higher the satisfaction level.

Abbreviated Name: SAT-P
Author(s): Giuseppina Majani , Simona Callegari
Purpose: To assess subjective satisfaction in daily life in clinical settings
Population: All
Type of Instrument: Satisfaction
Mode of Administration:

Rater:	Self-administered
Time required:	10 minutes
Response Options:	Visual Analog Scale (VAS)
Scoring:	Scores by dimension
	Scores by items
Score Direction:	Higher scores show better QoL

Number of Items: 32
Original Language: Italian
Existing Translations : English, French

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Contact for information and permission to use:

Edizioni Erickson,
Loc.Spini 154
38014 Gardolo - Trento
Italy
Phone: +39 0461 950690
Fax: 39 0461 950698
Website: http://www.erickson.it
E-mail: info@erickson.it

Dimensions covered by the questionnaire :

- Psychological functioning (10 items)
- Physical functioning (9 items)
- Work (5 items)
- Sleep/eating/leisure (5 items)
- Social functioning (3 items)

Key References:

1. Majani G, Callegari S, Piereobon A et al. A new instrument in quality of life assessment. The Satisfactory Profile (SAT-P).Int J Ment Health 1999;28:77-82.

2. Majani G, Piereobon A, Giardini A, Callegari S, Opasich C, Cobelli F, Tavazzi L. Relationship between psychological profile and cardiological variables in chronic heart failure. The role of patient subjectivity. Eur Heart J 1999;20:1579-1586.

Aim: To analyse the relationships between the psychological profile, the satisfaction profile and cardiological variables in patients with chronic heart failure. Material and Methods: One hundred and fifty-two male patients with chronic heart failure in a stable clinical condition underwent cardiological evaluation and psychological assessment by means of two instruments: the Cognitive Behavioural Assessment 2.0 Battery and the Satisfaction Profile. Results: Patients scored higher than healthy subjects in terms of psychophysiological disorders and depression. Patients in NYHA class III reported higher anxiety and depression scores and had more frequent problems in daily life than patients in NYHA classes I and II. Class III patients also reported lower satisfaction levels in many aspects of psychological and physical functioning. Pulmonary resistances >2.5 Wood units, pulmonary capillary wedge pressure >0. 18 mmHg and a diagnosis of ischaemic cardiomyopathy were associated with low satisfaction levels in the Satisfaction Profile 'physical functioning' factor. To be listed for heart transplantation and a history of more than three hospitalizations were related to low satisfaction levels in many items of the Satisfaction Profile. Finally, stepwise multiple regression showed that NYHA class, depression score and pulmonary capillary resistance accounted for 32% of the variance in the Satisfaction Profile physical functioning factor score. Conclusion: On the basis of chronic heart failure diagnosis only, a generic pattern of psychological distress can be predicted, common to many severe chronic diseases. Shifting from objective mental health measures towards the domain of subjective satisfaction, the only link which emerges is between objective cardiological data and satisfaction with physical functioning. Satisfaction in terms of other life aspects does not seem to be related to cardiological variables.These results support the importance of subjectivity in health related quality of life, as well as objective measures.

3. Majani G, Callegari S, Piereobon A, Giardini A. Presentation of a new instrument to assess satisfaction within health-related quality of life. Quality of life Newsletter. 1999;22:5-6.

4. Majani G, Baiardini I, Giardini A, Senna GE, Minale P, D'Ulisse S, Ciprandi G, Canonica GW. Health-related quality of life assessment in young adults with seasonal allergic rhinitis. Allergy. 2001; 56(4):313-7.

Background: In health-related quality of life (HRQL) studies on allergic rhinitis, both disease-specific and generic questionnaires have been extensively used. Seasonal allergic rhinitis (SAR) has been studied mainly by focusing on symptomatology. The present study aimed to evaluate the SAR-HRQL by means of two questionnaires, the Medical Outcome Study Short Form Health Survey (SF-36) and a new instrument examining satisfaction in 32 aspects of daily life: the Satisfaction Profile (SAT-P). Methods: Thirty-three patients with SAR (aged 33.5±8.5 years; 12 men, 21 women) were evaluated during and 2 months after the pollen season. Data were compared with reference samples by t-test, and baseline and follow-up HRQL scores were compared by a matched-pair test. Results: Patients' HRQL scores collected during the pollen season were

significantly lower than reference sample data in many SF-36 scores and in one SAT-P item. No differences emerged between SF-36 and SAT-P scores collected outside the pollen season and reference sample scores. Compared to baseline, outside the pollen season, patients reported significantly higher scores in the following SF-36 scales: physical functioning (P=0.002), physical role (P=0.00001), bodily pain (P=0.01), and vitality (P=0.008); and significantly higher scores in only two SAT-P items (physical well-being [P=0.009] and resistance to stress [P=0.01]). Conclusions: Our data confirm the utility of using symptomatologic and health-status questionnaires in evaluating the HRQL of SAR patients. More general quality of life questionnaires may prevent the symptomatologic and functional problems from being adequately recognized and managed. SAT-P can be a fruitful additional tool in HRQL evaluation.

SAT-P items and factors

I Psychological functioning

- Mood
- Mental efficiency
- Emotional stability
- Self-confidence
- Problem solving ability
- Psychological autonomy
- Self-control
- Social image
- Couple relationship
- Family role

II Physical functioning

- Resistance to physical fatigue
- Physical wellbeing
- Physical appearance
- Physical mobility
- Level of physical activity
- Frequency of sexual intercourse
- Quality of sexual intercourse
- Resistance to stress

III Work

- Type of work
- Organization of work
- Professional role
- Work productivity
- Financial situation

IV Sleep/eating/leisure

- Amount of sleep
- Quality of sleep
- Quality of food
- Eating behaviour
- Amount of spare time

V Social functioning

- Relationship with other members of your family
- Relationship with your friends
- Relationship with your colleagues

SCHEDULE FOR THE EVALUATION OF INDIVIDUAL QUALITY OF LIFE

The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) was developed based on the social judgment theory. The core idea of social judgment theory is that a person responds to stimuli in relation to the context in which they are perceived and a person's perception of an issue is dependent on the person's most preferred position (his/her anchor point), the person's judgment of the various alternatives and the person's level of ego-involvement with the issue. As to social judgement theory, the position of an individual on a certain statement can generally be categorised into one of the three zones, viz. *the latitude of acceptance* (zone of positions one accepts); *the latitude of non-commitment* (zone of positions one neither accepts nor rejects); and *the latitude of rejection* (zone of positions one rejects). Judgment analysis can be employed to quantify the relative importance of an array of factors to a particular judgment or position on a given issue. In brief, the investigator can assess the level of functioning in, and relative importance of, those areas of life nominated by the respondent.

The SEIQoL is a measure designed to elicit the value system of individual respondents and to quantify quality of life using this elicited system. This instrument is an interviewadministered measure with three structured stages. In the first stage, respondents are asked to select five domains of life (referred to as the "elicited cues") that they deem important in rela tion to their present quality of life. In the second stage, respondents are asked to rate the actual present status for all the "elicited cues" on a vertical visual analog scale (VAS), for example, a thermometer, and their overall quality of life on a horizontal VAS where 100 means as good as it could possibly be and 0 means as bad as it could possibly be. In so doing, individuals use their own idiosyncratic criteria to arrive at the relative ratings for each of the domains. In the final stage, the respondent ranks the overall quality of life for thirty (30) randomly generated hypothetical scenarios to quantify the relative contribution (the weighting) of each elicited cue to the overall judgment of quality of life of the individual. This task takes 30 minutes on average to complete. In the end, the relative weight attached to each cue is estimated by Partial Least Squares regression analysis using the Policy PC software and the weights sum to 1.0. A global, "elicited" quality of life score is then derived by multiplying each cue weight (level of importance to the individual) by the individual's current self-rating on that particular cue (level of satisfaction) and summing these across the five cues, with scores ?0 to 100. An overall single index of quality of life can be obtained by multiplying the individual VAS rating for each domain by the proportionate weight and summing the products. In this way a score of zero would represent the worst possible quality of life for that person and 100 would be the best.

The shorter version, Schedule for the Evaluation of Individual Quality of Life Direct Weighting (SEIQoL-DW) allows respondents to 'define' QoL by nominating the five most important aspects of their lives at that moment ('elicited cues') and by indicating the relative contribution ('weight') of each cue to their overall QoL. At different points in time, patients might nominate different 'cues' and might change their weighting of identical 'cues'. In their paper on different types of response shift, Sprangers and Schwartz (1999) have pointed out that both changes are indicative of a change of values.

Abbreviated Name: SEIQoL/ SEIQoL-DW
Author(s): O'Boyle CA, McGee H, Hickey A, Joyce CRB, Browne J, O'Malley K, Hiltbrunner B
Purpose: To assess quality of life from an individual perspective in healthy or ill individuals
Population: SEIQoL (long form) not for cognitively impaired persons
Age Range : 18 and over
Type of Instrument: Quality of life
Mode of Administration:

Rater:	SEIQo: Interview administered and self-administered in group settings SEIQoL-DW: Interview administered
Time required:	SEIQoL: ~30 Min / SEIQoL-DW: ~10 Min
Response Options:	Visual Analog Scale (VAS)
Scoring:	Global score: Minimum score: 0 / Maximum score: 100
Score Direction:	Higher scores show better QoL
Weighting:	Yes

Number of Items: 30
Original Language: English

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Contact for information and permission to use:

Royal College of Surgeons in Ireland Department of Psychology
C/o.Carole Caetano
Mercer Building
Lower Mercer Street
Dublin 2 Ireland

Dimensions covered by the questionnaire :

SEIQoL invites respondents to nominate the 5 areas currently most important to the person's quality of life; there are no restrictions on possible choices.

Key References:

1. Hickey AM, Bury G, O'Boyle CA et al. A New Short Form Individual Quality Of Life Measure (SEIQoL-DW): Application In A Cohort Of Individuals With HIV/AIDS. BMJ 1996;313:29-33

Quality of life is an increasingly important outcome measure in medicine and health care. Many measures of quality of life present patients with predetermined lists of questions that may or may not be relevant to the individual patient. This paper describes a brief measure, the SEIQoL-DW, which is derived from the schedule for evaluation of individual quality of life (SEIQoL). The measure allows respondents to nominate the areas of life which are most important, rate their level of functioning or satisfaction with each, and indicate the relative importance of each to their overall quality of life. Given its practicality and brevity, the measure should prove particularly useful in clinical situations where patient generated data on quality of life is important. This article describes the first clinical application of the measure, assessing the quality of life of a cohort of patients with HIV/AIDS managed in general practice.

2. O'Boyle CA. The Schedule for the Evaluation of Individual Quality of Life (SEIQoL). International Journal Of Mental Health 1994;23(3):3-23

3. McGee HM, O'Boyle CA, Hickey A et al. Assessing The Quality Of Life Of The Individual : The SEIQoL With A Healthy And A Gastroenterology Unit Population. Psychological Medicine 1991;21:749-759

Current methods of measuring quality of life (QoL) impose an external value system on individuals, rather than allowing them to describe their lives in terms of those factors which they consider important. The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) was developed to overcome such limitations. The QoL of 42 healthy attenders at an international immunization clinic was assessed using SEIQoL. Judgement reliability was high (r = 0.74) and individuals' judgement policies accounted for a large percentage of the variance in overall QoL (R2 = 0.75) demonstrating the construct validity of judgement analysis in this context. In a second study of QoL of out-patient suffering from irritable bowel syndrome (IBS) (N = 20) or peptic ulcer disease (PUD) (N = 20) was assessed using SEIQoL. Judgement reliability was lower (r = 0.54) although statistically highly significant (P less than 0.01), and the variance in overall QoL judgements explained was high (R2 = 0.74). SEIQoL is an acceptable, reliable and valid technique for measuring individual QoL that takes greater account of individual perspectives than traditional measurement approaches.

The Schedule for the Evaluation of Individual Quality of Life (SEIQoL)

Introduction

A team at the Royal College of Surgeons in Ireland, Department of Psychology have developed the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) to measure the individual's judgment of their quality of life (QoL) (O'Boyle et al. 1993; see also McGee et al. 1991; O'Boyle et al. 1992; Hickey et al. 1996; Browne et al. 1997). The propositions about QoL underlying the SEIQoL are shown in Table 1 and are discussed in more detail in Joyce, O'Boyle & McGee (1999).

Table 1. Propositions underlying the SEIQoL

1. QoL is individual in nature. Those aspects of life which are important to one person may have little or no relevance for another. Therefore, the only valid means of assessing QoL is by self-report.
2. An individual's judgment of their overall QoL is constructed from their assessment of their level of functioning/satisfaction in discrete domains of life which they consider to be important. Thus, a person's judgment of their QoL depends on their value system which, while generally stable over time, may change. The relative importance which a person attaches to particular aspects of life may change, for example, as they grow older, due to an illness or to some other change in their circumstances or their perception of their circumstances. The dynamic nature of the individual's QoL is central to our understanding of the concept.
3. In judging QoL, a person evaluates each important aspect of his or her life in terms of its relationship to worst and best possible states. This yardstick will also be specific to the individual and will be influenced by a variety of factors including experience and expectations.
4. Only the individual can validly judge his or her QoL. Assessment of QoL in health has been developed largely in the context of professional assessment of patients. Many measures of health status such as the Karnofsky Index and the QL-Index require the physician to rate the patient. Our perspective is that only the individual concerned can provide a comprehensive account of his or her own QoL. Assessments by others such as physicians or carers will be necessary in certain cases such as Alzheimer's disease, mental retardation, vegetative states or in the case of young children. However, these are proxy assessments and must not be confused with the individual's own assessment. This view is supported by studies documenting low levels of concordance between individual's ratings of their own QoL and the assessment of their QoL made by others, including physicians (see review by Sprangers & Aaronson 1992).

The SEIQoL is designed to measure three elements of QoL:

- Those aspects of life considered by the individual to be crucial to his/her QoL are elicited by means of a structured interview.
- Current status on each aspect is rated by the individual.

The relative importance of each aspect of QoL is measured, using Judgment Analysis, to derive the weight the individual assigns to each in judging overall QoL.

Judgment Analysis

In the SEIQoL, the relative importance of each aspect of life to overall QoL is measured using Judgment Analysis (JA). JA, also known as policy capturing, is a research method which has been widely used in studies of judgment and decision making. It externalizes the manner in which a person makes a judgment or decision (their 'judgment policy'), by using statistical methods to derive an algebraic model of the judgment process. The goal of JA is to quantify the relationships between a person's judgment and the information, or 'cues', used to make that judgment. The theoretical

foundations for JA lie in Brunswick's lens model and in Social Judgment Theory as developed by Hammond (Hammond, Stewart, Brehmer, and Steinmann 1975, Brehmer and Joyce 1988). Therefore, JA differs from other methods of deriving algebraic judgment models such as multiattribute utility theory, in that is the only method that is based on firm theoretical premises about how people cope with complex problems requiring judgment (Stewart 1988).

JA can be used, not just to model the judgment process, but also as an aid to such processes. It has been found particularly useful in externalizing the basis for judgment when people lack insight into the reasons for their judgment as is often the case in expert judgment and decision making.

SEIQoL Methodology

During a structured interview, respondents are asked to think about their lives and nominate the five areas of life (cues) which they consider most important to the overall quality of their lives (O'Boyle et al. 1993). The number of cues to be elicited was set at five as research indicates that most people experience difficulty in making judgments requiring combination of information from a larger number of cues (Stewart 1988). The meaning of each cue is recorded together with the label that the respondent uses for each cue. For example, different respondents may use "religion" as a cue label, but it can have various meanings: a spiritual activity, a social activity (meeting friends at services), or a physical activity reflecting mobility (being able to walk to services). The definition is important for subsequent understanding of what the respondent intended by the cue label. It is also important in summarizing cues from a number of respondents.

Respondents then rate their current status in each area against a vertical visual analogue scale, labeled at the upper and lower extremities by the terms as good as could possibly be and as bad as could possibly be, respectively. The interviewer generates a profile using bar charts based on the respondent's ratings. The respondent is asked to consider the profile and rate their global QoL on a horizontal visual analogue scale. At this stage of the procedure, the interviewer knows which areas of life are most important to the respondent and his or her current status on each. In order to quantify the relative importance of each cue, JA is used. The respondent is presented with thirty randomly generated profiles of hypothetical subjects labeled using the five previously chosen cues and asked to rate the global QoL for each profile. It is estimated that 10 cases are required to derive a judgment policy with three uncorrelated cues and a further 5 cases for each additional cue thus requiring 20 cases for 5 cues (Stewart 1988; O'Boyle et al. 1993). Ten further repeated cases are included in order to estimate internal reliability. The relative weight attached by the respondent to each cue in judging global QoL is calculated by multiple regression (Policy PC, 1986). The SEIQoL thus allows determination of the areas the respondent considers important, current functioning in each area and the relative importance of each area.

The Policy PC programme which is used to derive weights also computes the statistic R2, a measure of the variance in overall QoL judgments explained by the five cues used. This statistic provides an estimate of the internal validity of JA. The internal reliability may be calculated by correlating repeat case judgments. Therefore, the investigator can assess how well the particular judgment policy models the individual's assessment of QoL (R2) and also how reliably the individual uses the policy (r).

Appropriate Respondents and Applications

Most existing measures of QoL are health related in that they have been designed to assess the impact of illness and treatment on the quality of life of patients, or significant others related to the patient. They reflect a 'disease' model which is primarily concerned with the measurement of health status and the health outcome of treatment interventions and care (Spilker 1990; Bowling 1991). In the SEIQoL, the terms of reference are determined entirely by the individual. The technique may therefore be used for measuring QoL across a wide range of medical conditions and in healthy individuals and should be free from cultural bias, although this has not yet been investigated empirically.

The applicability of the SEIQoL may be limited in illnesses which impair cognitive functioning or motivational state (Coen et al. 1993). Successful completion requires, inter alia, insight into the factors which determine one's QoL, the ability to think abstractly, the ability to make judgments based on information presented in diagrammatic form, and the ability to provide ratings using vertical and horizontal visual analogue scales (O'Boyle et al, 1993). Therefore, its use with patient groups in whom these abilities are impaired may be problematic and may necessitate modification of the standard form of the SEIQoL or use of another respondent such as a caregiver or 'significant other'. In such cases the estimate of QoL will be indirect and should be designated as such.

While the SEIQoL is intended to be used as an individual measure, group comparisons may require a single index. A global QoL score can be calculated by multiplying the relevant cue weights by the individual's current self-rating and summing across the five cure (QoL = 91 (levels X weights). As this global QoL index is a continuous measure ranging from 0 to 100 it can be analysed using parametric statistical methods. Care is needed in interpreting the global score as it is the sum of the products of individual cue levels by cue weights, each of which may vary independently.

SEIQoL Administration

The SEIQoL (using JA) takes about 30 minutes to administer and requires the POLICY PC computer programme to evaluate the individual's judgments. A parallel methodology where the JA task has been replaced with a disk has been developed. The 'direct weighting procedure' (SEIQoL-DW) involves having individuals manipulate a 5-section disk to display areas representing the relative value, or weight, they give to each elicited cue. Weights are then read directly from calibrations on the disk. The remainder of the methodology is as before (See Hickey et al. 1996; Browne et al. 1997).

The SEIQoL is being used in a variety of research settings internationally.

For the latest information about ongoing research please contact the authors.

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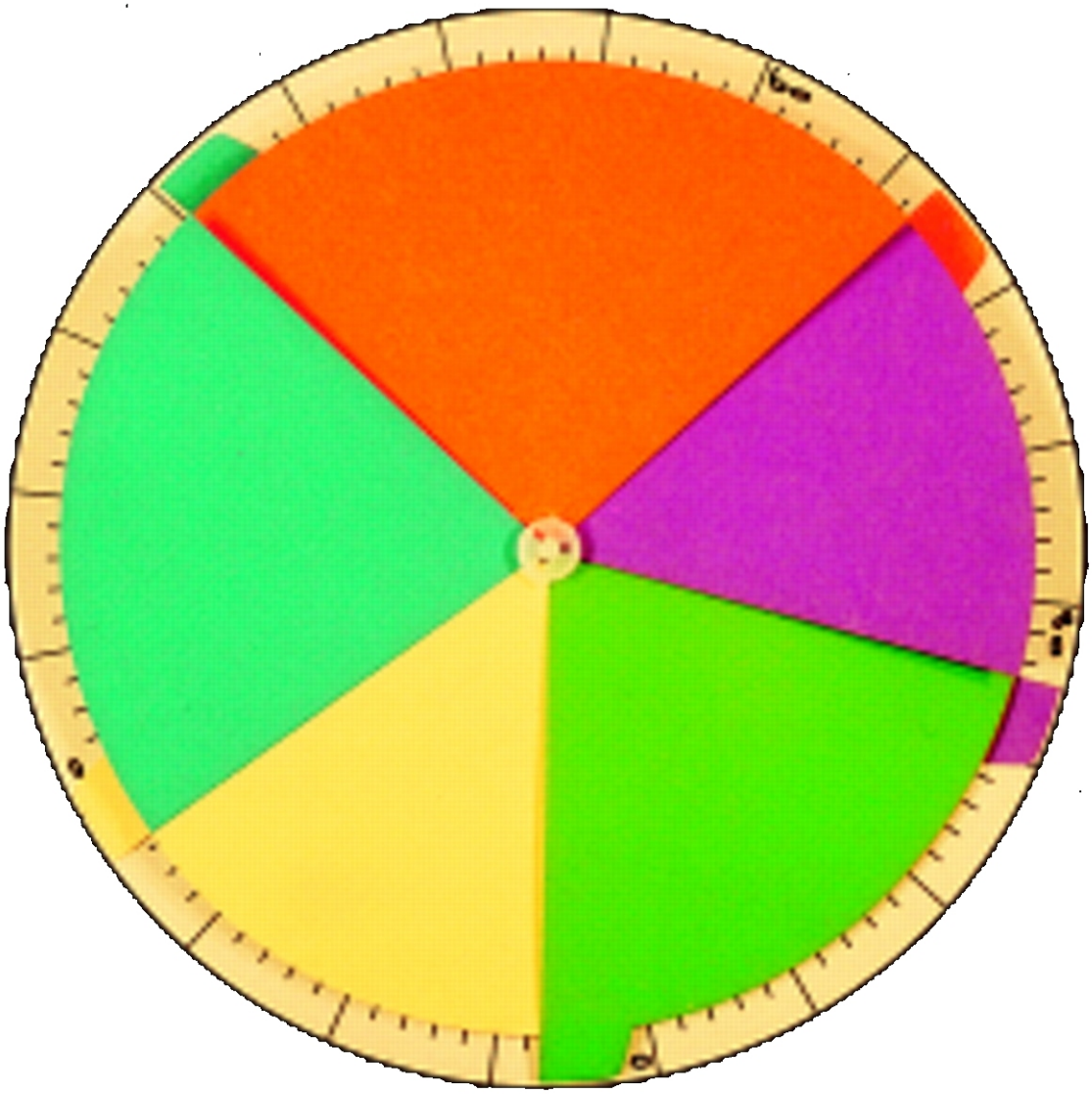
SEIQoL: Ordering

The SEIQoL Manual is available from the

Department of Psychology,
Royal College of Surgeons in Ireland,
Mercer Building Dublin 2, Ireland
E-mail: ccaetano@rcsi.ie



SELF-EVALUATION OF QUALITY OF LIFE

The SEQOL questionnaire is a self-administered questionnaire with items rated on a five-point Likert scale. The questionnaire consists of 317 items based on an "integrative" theory of the quality of life, meaning that it organizes a number of theories on the quality of life into a spectrum that spans the extremes of subjective and objective quality of life.

Abbreviated Name: SEQOL
Author(s): Søren Ventegodt, Joav Merrick, Niels J Andersen
Purpose: Describing the quality of life of a population or patient group
Population: Adult
Age Range : 18 and over
Type of Instrument: Quality of Life
Mode of Administration:

Rater:	Self-administered
Time required:	20-30 minutes
Response Options:	Likert scale and Yes/No
Scoring:	Global score Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 317
Original Language: English

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Contact for information and permission to use:

Søren Ventegodt MD, MMedSci
Quality-of-Life Research Center,
Nordic School of Holistic Medicine &
Research Clinic for Holistic Medicine
/Forskningscenter for Livskvalitet
Teglgårdsstræde 4-8
1452K København/Copenhagen
Phone + 45 33 14 11 13
FAX: + 45 33 14 11 23
E-mail: ventegodt@livskvalitet.org
Web: http://www.livskvalitet.org

Prof Joav Merrick, MD, MMedSci, DMSc
Division for Mental Retardation
Ministry of Social Affairs
POBox 1260
IL-91012 Jerusalem, ISRAEL
Tel: 972-2-6708122
Fax: 972-2-6703657
Mobile: 972-50-6223832
E-mail: jmerrick@internet-zahav.net
Website: www.nichd-israel.com

Dimensions covered by the questionnaire :

I. Subjective Dimensions

- Immediate, self-experienced well-being
- Satisfaction with life
- Happiness

II. Existential Dimensions

- Needs fulfillment
- Subjective experience of objective temporal domains (family, work, leisure)
- Subjective experience of objective spatial domains (satisfaction with social relationships)
- Expression of life's potentials

III. Objective Dimension

- Objective factors (income, employment, education, etc.)

Key References:

5. Ventegodt S, Henneberg EW, Merrick J, Lindholt JS. Validation of Two Global and Generic Quality of Life Questionnaires for Population Screening: SCREENQOL and SEQOL. The Scientific World Journal 2003; 3: 412-421

Population screening may harm quality of life (QoL), and traditional health-related QoL tools could be inadequate to evaluate this risk. Two global and generic QoL instruments were developed for studying the QoL consequences of screening (SCREENQOL), and QoL variation in a normal population (SEQOL). SCREENQOL and SEQOL (Self-Evaluation of Quality of Life Questionnaire) are self-administered questionnaires with items rated on 5-point Likert scales. SCREENQOL consists of 21 items measuring QoL across 6 different dimensions based upon validated QoL questionnaires. SEQOL consists of 317 items measuring QoL across 8 different dimensions, based on an integrative theory of QoL, a theoretical framework from a Danish QoL survey involving 7,222 persons 31 to 33 years old. For further validation, SEQOL and SCREENQOL were sent to 2,460 persons 18 to 88 years old randomly selected from the Danish Central Person Register together with Nottingham Health Profile (NHP) and Sickness Impact Profile (SIP). For SCREENQOL and SEQOL, test-retest reliability correlation was both >0.8, Cronbach's alpha was 0.65 and 0.75, correlation (r) to NHP was 0.67 and 0.49, to SIP 0.46 and 0.27, respectively ($p < 0.05$). Adjustment for health status made the correlation to SIP stronger among the sick ($r = 0.68$ and 0.41, respectively). For SCREENQOL and SEQOL, 61 and 111 respondents were needed to detect 3% difference in QoL. SCREENQOL and SEQOL are both valid as they show high levels of reliability, sensitivity, and consistency.

6. Ventegodt S, Merrick J, Andersen NJ. Measurement of Quality of Life III. From the IQOL Theory to the Global, Generic SEQOL Questionnaire The Scientific World Journal 2003; 3: 972-991

The Danish Quality of Life Survey is based on the philosophy of life known as the integrative quality-of-life (IQOL) theory. It consists of eight different quality-of-life concepts, ranging from the superficially subjective via the deeply existential to the superficially objective (well being, satisfaction with life, happiness, meaning in life, biological order, realizing life potential, fulfillment of needs, and objective factors [ability of functioning and fulfilling societal norms]). This paper presents the work underlying the formulation of the theories of a good life and how these theories came to be expressed in a comprehensive, multidimensional, generic questionnaire for the evaluation of the global quality of life — SEQOL (self-evaluation of quality of life) — presented in full length in this paper. The instruments and theories on which the Quality of Life Survey was based are constantly being updated. It is an on-going process due to aspects such as human development, language, and culture. We arrived at eight rating scales for the quality of life

that, guided by the IQOL theory, were combined into a global and generic quality-of-life rating scale. This was simplified to the validated QOL5 with only five questions, made for use in clinical databases. Unfortunately, the depth of human existence is to some extent lost in QOL5. We continue to aim towards greater simplicity, precision, and depth in the questions in order to explore the depths of human existence. We have not yet found a final form that enables us to fully rate the quality of life in practice. We hope that the several hundred questions we found necessary to adequately implement the theories of the Quality of Life Survey can be replaced by far fewer; ideally, only eight questions representing the eight component theories. These eight ideal questions have not yet been evaluated, and therefore they should not form the basis of a survey. However, the perspective is clear. If eight simple questions can accurately rate the quality of life as well as its depth, we have found an instrument of immense practical scope.

7. Ventegodt S, Hilden J, Merrick J. Measurement of Quality of Life I. A Methodological Framework The Scientific World Journal 2003; 3: 950-961

Despite the widespread acceptance of quality of life (QOL) as the ideal guideline in healthcare and clinical research, serious conceptual and methodological problems continue to plague this area. In an attempt to remedy this situation, we propose seven criteria that a quality-of-life concept must meet to provide a sound basis for investigation by questionnaire. The seven criteria or desiderata are: (1) an explicit definition of quality of life; (2) a coherent philosophy of human life from which the definition is derived; (3) a theory that operationalizes the philosophy by specifying unambiguous, nonoverlapping, and jointly exhaustive questionnaire items; (4) response alternatives that permit a fraction-scale interpretation; (5) technical checks of reproducibility; (6) meaningfulness to investigators, respondents, and users; and (7) an overall aesthetic appeal of the questionnaire. These criteria have guided the design of a validated 5-item generic, global quality-of-life questionnaire (QOL5), and a validated 317-item generic, global quality-of-life questionnaire (SEQOL), administered to a well-documented birth cohort of 7,400 Danes born in 1959–1961, as well as to a reference sample of 2,500 Danes. Presented in outline, the underlying integrative quality-of-life (IQOL) theory is a meta-theory. To illustrate the seven criteria at work, we show the extent to which they are satisfied by one of the eight component theories. Next, two sample results of our investigation are presented: satisfaction with one's sex life has the expected covariation with one's quality of life, and so does mother's smoking during pregnancy, albeit to a much smaller extent. It is concluded that the methodological framework presented has proved helpful in designing a questionnaire that is capable of yielding acceptably valid and reliable measurements of global and generic quality of life.

8. Ventegodt S, Kandel I, Merrick J. Principles of Holistic Medicine: Global Quality of Life Theory, Research and Methodology. Hippocrates Scientific Publications New Hyde Park, New York. 2005.

9. Ventegodt S, Kandel I, Merrick J. Principles of Holistic Medicine: Quality of Life and Health. Hippocrates Scientific Publications New Hyde Park, New York. 2005.

The SEQOL (Self-Evaluation of Quality of Life) Questionnaire

About the Questionnaire

The concept of the quality of life has become a central concept in health care with many Doctors becoming more interested in increasing the quality of life of their patients. We have developed this questionnaire to examine the connection between quality of life and illness.

An (m) or an (f) after a question denotes that it is to be answered by men or women respectively.

At the end of the questionnaire we would like to know how you felt about filling in the questionnaire. Space has been provided for any comments you may have on the questionnaire or any personal reflections you may have on quality of life. All comments will be read carefully.

Please consider every question carefully before answering. It is important to the investigation that you answer honestly. We recommend that you fill out the questionnaire alone.

Please try to answer all the questions unless, of course, you find them too unpleasant, in which case you do not have to answer.

The answers to the questionnaire are anonymous and the information provided by these questionnaires is processed electronically and governed by the Danish Act on Information Held in Record Systems; this investigation is regulated by the Danish Data Surveillance Authority

Instructions for filling out the Questionnaire

Please note that some of the questions deal with your subjective opinion whereas others deal with factual, objective matters. Most questions can be answered by simply circling the number that is placed next to the answer you have chosen (vertically or horizontally), for instance:

9	**Sex:**	(1)	Female
		2	Male

Where lines have been left open, please answer in words or numbers or give your opinion.

The answers are anonymous
Please answer all the questions
Thank you for your help

© 2003 The Quality of Life Research Centre. The questionnaire is hereby released for non-commercial, scientific use. Please apply for written permission for all commercial or non-scientific use to the Quality of Life Research Centre (www.livskvalitet.org).

Personal information

Please note that you are **not** to write your name on the questionnaire! Your reply is anonymous.

6-8 Today's date:

9 Sex: 1 female
2 male

10 Age:_____years

11 Height:_____cm

12 Weight:_____kg

13 What is your marital status?

1	single	4	separated
2	living with partner	5	divorced
3	married	6	widowed

14 With **whom** do you live? (Please circle all that apply)

1 living alone
2 spouse or partner
3 own children
4 partner's children
5 adopted children
6 friends
7 biological parents
8 others
9 dog
10 cat
11 other domestic pet

15-16 Where do you live?

1	Copenhagen	3	In a village
2	In a large town (or suburb) of Copenhagen	4	In the country

Geographical location:
Postal Code

17 Type of housing:

1 own house
2 owner-occupied flat
3 cooperative
4 rented house
5 rented flat
6 rented room
7 student hostel (dormitory)
8 collective
9 others

18 If you are currently receiving training or **education**, please specify the type:
_____

19-24 List any higher **education** or vocational **training** you have completed also indicating the duration of each course embarked upon (for example, vocational training - 30 months; apprenticeship - 30 months; university degree - 36 months):

_____ months :____
_____ months :____
_____ months :____

25-30 If you have a partner, please list the education and training that he or she has completed.

_____ months :____
_____ months :____
_____ months :____

31-34 Your **occupation** . Please describe your occupation as precisely as possible (for example, farm owner instead of farmer, apprentice electrician instead of electrician):
_____

What does your work consist of?_____
_____
_____

Please describe your partner's **occupation** (if you have a partner):
_____

What does your partner's work consist of?_____
_____

35-36 What is your (and your partner's) **occupational status**? (Please circle one number in each column. If you are unemployed please refer to the occupation you have had for the longest period of time.)

	You	Your partner
self-employed	1	1
assistant in spouse's business	2	2
unskilled/ semi-skilled worker	3	3
skilled worker	4	4
homemaker	5	5
salaried employee or civil servant	6	6
student	7	7
pensioner	8	8
receiving welfare benefits	9	9

37-38 If you or your partner have **employees or subordinates**, please state how many:
_____yourself _____your partner

39 Current sector in which you are **employed:**

1	public	3	unemployed
2	private unemployed	4	other

40-41 What was the total income before taxes for yourself and your partner last year? (Please circle a number in each column)

		your-self	your partner
0	- 5.000 Euro/USD	1	1
5.001	-10.000 Euro/USD	2	2
10.001	-20.000 Euro/USD	3	3
20.001	-40.000 Euro/USD	4	4
40.001	-80.000 Euro/USD	5	5
over 80.000 Euro/USD		6	6

42 Does your **household** have any of the following durable consumer goods?

1 telephone
2 television
3 computer
4 videocassette recorder
5 washing machine
6 summer cottage
7 car
8 motorcycle
9 boat

43 How would you describe your **current financial and material situation**?

1 very good
2 good
3 neither good nor poor
4 poor
5 very poor

Lifestyle

44 How many hours of exhausting **exercise** (heavy breathing and sweating) do you get **a week**? (including during work)

1 0 hours
2 about 30 minutes
3 about 1 hour
4 about 2 hours
5 3-7 hours
6 8 hours or more

45 Your **social network**: how many close friends or family members do you have **daily contact** with (for example, see them or talk to them on the telephone)?

1 none
2 1 a day
3 2 a day
4 3 a day
5 4 or more

46 Do you have a friend with whom you can discuss any subject - and do?

1 yes 2 not sure 3 no

47 Your **eating habits**?
(Please circle the lines that apply to you)

1 I eat what I like
2 I think my diet is healthy
3 I think my diet is not healthy enough
4 I have a low-calorie diet to maintain or lose weight
5 I eat ready-to-eat dishes or fast food at least once a week
6 I am a vegetarian
7 Information campaigns influence my eating habits

48-52 How much **alcohol** did you drink in the last complete weekday (Monday, Tuesday, Wednesday or Thursday)?

ordinary beer (number of 33-cl bottles): _____
strong beer (number of 33-cl bottles): _____
red or white wine (number of glasses): _____
dessert wine (number of glasses): _____
spirits (number of drinks): _____

53-57 How much **alcohol** did you drink **in total last weekend** (including Friday, Saturday and Sunday)?

ordinary beer (number of 33-cl bottles): _____
strong beer (number of 33-cl bottles): _____
red or white wine (number of glasses): _____
dessert wine (number of glasses): _____
spirits (number of drinks): _____

58 Was your **alcohol** consumption **typical** of your normal level in the past week?

1 yes
2 no, more than typical
3 no, less than typical

59-63 Do you smoke?

1 yes, daily
2 yes, now and then
3 no, I stopped less than a year ago
4 no, I stopped more than a year ago
5 no, I have never smoked

If yes, **how much do you smoke on average:**

number of cigarettes daily _____
number of cheroots daily _____
number of cigars daily _____
amount of smoking tobacco (grams) ____

64 Have you ever tried any of the following **drugs**:

1 hash
2 LSD
3 psilosybin (mushrooms)
4 mescaline (cactus)
5 amphetamine, speed
6 cocaine
7 crack
8 ecstasy
9 methadone
10 heroin, morphine
11 tranquilizers with alcohol
12 none

Illness

65 -66 In relation to your **health**, how do you feel **now**? (Please circle a number in each column)

	physical health	mental health
very well	1	1
well	2	2
neither well nor ill	3	3
ill	4	4
very ill	5	5

67 In the **last year**, how many days of work have you missed due to **illness**? (Or, if you are unemployed, how many days would you have been too ill to work had you been in employment?)

1	0 - 3	days	4	31 - 100	days
2	4 - 10	days	5	101 - 300	days
3	11 - 30	days	6	301 - 365	days

68. If you suffer from illness or a health problem do you try to treat it by changing your outlook on life or your lifestyle?

1 no 2 not sure 3 yes

69 Do you receive alternative health care now?

1 yes
2 no, but i did previously
3 no, and i have never received it

70 Have you ever undergone an operation under full **anesthesia**?

1 no 2 not sure 3 yes

71-86 Do you have any of the following health problems **now**? (Please circle a number in each row)

	no	yes, some-what	yes, a lot
pain or discomfort in shoulder or neck?	1	2	3
pain or discomfort in back or buttocks?	1	2	3
pain or discomfort in arms or hands, legs, knees, hips or joints?	1	2	3
headache	1	2	3
a rapid heart beat?	1	2	3
uneasiness nervousness, restlessness or anxiety?	1	2	3
stress	1	2	3
difficulty sleeping (insomnia)?	1	2	3
melancholy, depression or unhappiness?	1	2	3
tiredness?	1	2	3
stomach pain or stomachache?	1	2	3
indigestion, diarrhea or constipation?	1	2	3
eczema, rash, or itching?	1	2	3
cold, head cold, or cough?	1	2	3
difficulty in breathing or breathlessness?	1	2	3
discomfort in the sexual organs(f)	1	2	3

87 Did the health problems have anything to do with a certain illness or the treatment of it?

1 no 2 not sure 3 yes

88-90 Do you have an **illness or disorder** for which you are receiving medical treatment now?

1 no 2 yes

If yes: please state, as accurately as possible, the **diagnosis** of the illness or the nature of the handicap: (such as pollen allergy or depression)

_____

_____

What treatment or **medication** are you receiving? (Please write the brand name)

_____

_____

_____

_____

91-123 Do you have any of the following illnesses or disorders **now**? (Please circle a number in each line)

	no	yes
impaired hearing	1	2
impaired sight	1	2
back problems	1	2
diabetes	1	2
mental illnesses	1	2
epilepsy	1	2
paralysis in any part of the body	1	2
high blood pressure	1	2
coronary thrombosis	1	2
cerebral hemorrhage or cerebral thrombosis	1	2
chronic bronchitis	1	2
allergy (not hayfever)	1	2
hayfever	1	2
eczema	1	2
psoriasis	1	2
lupus erythematosus	1	2
ulcer	1	2
gallstones	1	2
kidney stones	1	2
HIV-positive	1	2
AIDS	1	2
cancer	1	2
congenital illnesses	1	2
amputation of arms or legs	1	2
venereal diseases	1	2
anorexia/bulimia	1	2
removal of a tumor in the breast (f)	1	2
removal of the entire breast (f)	1	2
menstrual problems (f)	1	2
diseases of the female sexual organs (not venereal diseases) (f)	1	2
had a cone biopsy performed (f)	1	2
had your uterus removed (f)	1	2

124 Have you ever had an abortion? (f)

1 no 3 yes, twice
2 yes, once 4 yes, 3 or more times

125 Have you ever had a miscarriage? (f)

1 no 2 not sure 3 yes

Sexuality

126 Are you sexually active?

1 yes 2 no

127 How **satisfied** are you with your sex life now?

1 very satisfied
2 satisfied
3 neither satisfied nor dissatisfied
4 dissatisfied
5 very dissatisfied

128 Sexual orientation:

1 heterosexual (attracted to the opposite sex)
2 bisexual (attracted to both sexes)
3 homosexual (attracted to your own sex)

129-137 Do you have sexual problems?

1 no
2 yes, but they are not connected to any prolonged illness or disability
3 yes, and they are connected to a prolonged illness or disability

If yes, what is your problem: (please circle a number in each line)

	yes	not sure	no
lack of a suitable sexual partner	1	2	3
reduced sexual desire	1	2	3
pain or discomfort during intercourse	1	2	3
unable to achieve orgasm	1	2	3
decreased ability to achieve erection(m)	1	2	3
premature ejaculation (m)	1	2	3
involuntary vaginal spasms severe enough to prevent intercourse (vaginism) (f)	1	2	3
other	1	2	3

Your Perception of Yourself

138-173 Do you feel you are (please circle a number in each line):

	yes	not sure	no
healthy	1	2	3
physically strong	1	2	3
in harmony with yourself	1	2	3
honest	1	2	3
sensitive	1	2	3
loving	1	2	3
beautiful	1	2	3
sexually attractive	1	2	3
loved	1	2	3
cheerful	1	2	3
open	1	2	3
sociable	1	2	3
good	1	2	3
free	1	2	3
ethical	1	2	3
with a sense of humor	1	2	3
intelligent	1	2	3
sensible	1	2	3
patient	1	2	3
psychologically strong	1	2	3
independent	1	2	3
strong-willed	1	2	3
competent	1	2	3
ambitious	1	2	3
involved	1	2	3
creative	1	2	3
responsible	1	2	3
conscientious	1	2	3
filled with fighting spirit	1	2	3
brave	1	2	3
self-confident	1	2	3
a success	1	2	3
profound	1	2	3
intuitive	1	2	3
spiritual	1	2	3
sincere	1	2	3

Your Perception of Life

174-194 (please circle a number in each line)

	yes	not sure	no
do you feel comfortable in your body?	1	2	3
do you accept yourself as you are?	1	2	3
are you happy most of the time?	1	2	3
do you find your life boring?	1	2	3
do you have negative thoughts about your life several times a day ?	1	2	3
do you often worry?	1	2	3
do you often regret your actions?	1	2	3
do you often feel lonely?	1	2	3
do you sometimes think of committing suicide?	1	2	3
do you think that other people speak well of you?	1	2	3
do you easily adjust to new situations?	1	2	3
do you see problems as a challenge?	1	2	3
do you feel your life is a success?	1	2	3
is there accordance between your thought words and actions?	1	2	3
do you feel free to choose what your life is going to be like?	1	2	3
do you feel happy and look forward to starting a new day when waking up in the morning?	1	2	3
do you blame others for your unhappiness?	1	2	3
do you forgive others easily?	1	2	3
do you feel that fate has treated you badly?	1	2	3
do you feel that your life has meaning?	1	2	3
do you feel that you are part of a greater whole?	1	2	3

Quality of Life

195-210 My life mainly focuses on:
(please circle a number in each line)

	yes	not sure	no
surviving	1	2	3
making money	1	2	3
my job	1	2	3
being creative	1	2	3
sex	1	2	3
feeling good	1	2	3
fulfilling my needs	1	2	3
my relationship with my partner	1	2	3
my children or having children	1	2	3
having good friends	1	2	3
living in harmony with myself	1	2	3
self-realization	1	2	3
my career	1	2	3
making the world a better place	1	2	3
serving God	1	2	3

others:

211 How are you **feeling** now?

1 very good
2 good
3 neither good nor poor
4 poor
5 very poor

212 How **satisfied** are you with your life now?

1 very satisfied
2 satisfied
3 neither satisfied nor dissatisfied
4 dissatisfied
5 very dissatisfied

213 How **happy** are you now?

1 very happy
2 happy
3 neither happy nor unhappy
4 unhappy
5 very unhappy

214 How would you assess the **quality of your life now?** (base your answer on what you believe quality of life to be)

1 very high
2 high
3 neither high nor low
4 low
5 very low

Section A

The following questions concern your **current satisfaction** with life. Please answer all questions even if you do not have parents, a partner nor children.

215-224 At present how satisfied are you with: (Please note that you can be satisfied even with, for instance, poor health.)

	very satisatisfied	satis-fied	neither /nor	dis satis'	very dis'
your **health**?	1	2	3	4	5
your **material and financial situation**?	1	2	3	4	5
your situation with your **partner?**	1	2	3	4	5
your **parents** (please answer even if your parents are not alive) ?	1	2	3	4	5
your situation with regard to **children** (please answer even if you do not have children)?	1	2	3	4	5
your relationships with **friends**	1	2	3	4	5
your relationships with **acquaintances**?	1	2	3	4	5
the **community** around you?	1	2	3	4	5
nature in your local environment?	1	2	3	4	5
your job situation	1	2	3	4	5

225 How well did Section A (questions 215-224) enable you to express **your quality of life?**

1 very well
2 well
3 neither well nor poorly
4 poorly
5 very poorly

Section B

226-227 Do you have a **partner**?

1 yes
2 not sure
3 no, but I have had one.
4 no, and I have never had one

If yes, how long have you been with your present partner?

1 0-1 year
2 1-2 years
3 2-3 years
4 3-5 years
5 5-10 years
6 10-25 years
7 more than 25 years

228-248 Do you have **children**?
(If necessary, please circle more than one number)

1 yes, biological children
2 yes, my partner's children
3 yes, adopted children
4 no, but I or my partner is pregnant
5 no, I/we are involuntarily childless
6 no, I/we have chosen not to have children
7 no

If yes, please state the **sex** and **age** of your children:

	boy	girl	age
1st child (oldest)	1	2	
2nd child	1	2	
3rd child	1	2	
4th child	1	2	
5th child	1	2	

Did you have these children with your present partner?

	yes	no
1st child (oldest)	1	2
2nd child	1	2
3rd child	1	2
4th child	1	2
5th child	1	2

Are you living with your children?

	yes	no
1st child (oldest)	1	2
2nd child	1	2
3rd child	1	2
4th child	1	2
5th child	1	2

249 Were you **adopted** as a child?

1 no 2 not sure 3 yes

250 Are both your **parents** (or adoptive parents) **alive**?
1 yes
2 no, only one of them
3 no, none of them
4 do not know

251-260 How many **brothers and sisters** (or half brothers and half sisters) **do you have and how old are they**:

	brother	sister	half brother	half sister	age
1st sibling (oldest)	1	2	3	4	
2nd sibling	1	2	3	4	
3rd sibling	1	2	3	4	
4th sibling	1	2	3	4	
5th sibling	1	2	3	4	

261 Are you a **twin**?

1 no 3 yes, fraternal
2 no, triplet 4 yes, identical

262 -296 A good relationship consists of:

- good and useful communication
- an emotional fellowship
- being equal, open and honest toward each other
- being able to talk about all important issues
- a relationship that is not characterized by unresolved conflicts, suppression and dominance or sexual problems.

Compared with this, how good is your current relationship with: (Circle the numbers which suit your life. Please leave out people you have never been in contact with or who are dead)

	Very good	good	Neither /nor	Poor	Very Poor
your present partner	1	2	3	4	5
your last partner	1	2	3	4	5
your previous partners	1	2	3	4	5
1st child (oldest)	1	2	3	4	5
2nd child	1	2	3	4	5
3rd child	1	2	3	4	5
4th child	1	2	3	4	5
5th child	1	2	3	4	5
biological father	1	2	3	4	5
biological mother	1	2	3	4	5
stepfather	1	2	3	4	5
stepmother	1	2	3	4	5
adoptive father	1	2	3	4	5
adoptive mother	1	2	3	4	5
maternal grandmother	1	2	3	4	5
maternal grandfather	1	2	3	4	5
paternal grandmother	1	2	3	4	5
paternal grandfather	1	2	3	4	5
1st sibling (oldest))	1	2	3	4	5
2nd sibling	1	2	3	4	5
3rd sibling	1	2	3	4	5
4th sibling	1	2	3	4	5
5th sibling	1	2	3	4	5
partner's father	1	2	3	4	5
partner's mother	1	2	3	4	5
partner's siblings	1	2	3	4	5
partner's friends	1	2	3	4	
your grandchildren	1	2	3	4	5
your other relatives	1	2	3	4	5
your friends	1	2	3	4	5
your fellow workers	1	2	3	4	5
your acquaintances	1	2	3	4	5
yourself	1	2	3	4	5
the community around you	1	2	3	4	5
nature around you	1	2	3	4	5

297 How well does Section B (questions 226-296) enable you to express **your quality of life?**

1 very well
2 well
3 neither well nor poorly
4 poorly
5 very poorly

Section C

The following questions deal with family, work and leisure time.

298 How do you feel when you are at home?

1 very good
2 good
3 neither good nor poor
4 poor
5 very poor

299 How do you feel when you are at work
(if you do not have a job, how do you feel in your everyday life)?

1 very good
2 good
3 neither good nor poor
4 poor
5 very poor

300 How do you feel in your **leisure time?**

1 very good
2 good
3 neither good nor poor
4 poorly
5 very poor

301 How well does Section C (questions 297-299) enable you to express **your quality of life?**

1 very well
2 well
3 neither well nor poorly
4 poorly
5 very poorly

302-303 How good is your work environment?
(If you do not have any work, please go to the next question)

	socially	physically
very good	1	1
good	2	2
neither good nor poor	3	3
poor	4	4
very poor	5	5

304 Do you feel that your work is **meaningful?**
(If you do not have any work, please assess your normal daily activities)

1. very meaningful
2 meaningful
3 neither meaningful nor meaningless
4 meaningless
5 very meaningless

Section D

The following questions deal with how well your needs are fulfilled.

305 How well are your **basic biological needs** being **fulfilled now**? (that is. your physical needs such as food, clothing, heating, housing, sleep, sex, safety and security .)

1 very well
2 well
3 neither well nor poorly
4 poorly
5 very poorly
6 I do not have these needs

306 How well are your **social needs** being fulfilled now?

(that is, your needs for warm human contact, recognition, friendship and social acceptance).

1 very well
2 well
3 neither well nor poorly
4 poorly
5 very poorly
6 I do not have these needs

307 How well is your **need to be useful** being **fulfilled now** (that is, your need to help other people and your contribution to making the world a better place)?

1 very well
2 well
3 neither well nor poorly
4 poorly
5 very poorly
6. I do not have this need

308 How well is your need for an **exciting and varied life** being fulfilled now (that is, your need to have an exciting and varied life with various experiences and actions)?

1 very well
2 well
3 neither well nor poorly
4 poorly
5 very poorly
6 I do not have these needs

309 How well is your **need to realize you life potential** being fulfilled now (that is, your need to

develop insight and the ability to take action that will enable you to live in ever increasing harmony with yourself)?

1 very well
2 well
3 neither well nor poor
4 poorly
5 very poorly
6 I do not have these needs

310 How well does section D (questions 303-309) enable you to express **your quality of life?**

1 very well
2 well
3 neither well nor poorly
4 poorly
5 very poorly

311 How well are **your needs** being fulfilled now

1. very well
2. well
3 neither well nor poorly
4 poorly
5 very poorly

312 How many of the following societal norms do you fulfill now? (Societal norms here means having a) a job; b) education c) nuclear family; and d) at least 2 friends in whom you can confide everything and do so.)

1 all four
2 three of four
3 two of four
4 one of four
5 none

313 How good **is your peace of mind** (your inner equilibrium and state of health) now?

1 very good
2 good
3 neither good nor poor
4 poor
5 very poor

314 How well are you realizing your **deepest desires** now?

1. very well
2. well
3 neither well nor poorly
4 poorly
5 very poorly

315 How **meaningful** is your life now?

1 very meaningful
2 meaningful
3 neither meaningful nor meaningless
4 meaningless
5 very meaningless

Evaluation and criticism of the questionnaire (1-315)

316 How **easy** did you find it to fill out the questionnaire?

1 very easy
2 easy
3 neither easy nor difficult
4 difficult
5 very difficult

317 Did you find it **strenuous** to fill out the questionnaire?

1 not strenuous
2 strenuous
3 very strenuous

318 How was your mood when you filled out the questionnaire

1 better than usual
2 usual
3 worse than usual

319 How **long** did it take you to fill out the questionnaire?

1 less than 30 minutes
2 30 minutes to 1 hour
3 1-2 hours
4 2-4 hours
5 more than 4 hours

320-321 While going through the questionnaire, did you come across any questions you felt we should not have asked? (**unethical** questions)?

1 no 2 not sure 3 yes

If yes or in doubt, please explain the reason:(please note the number of the question)

322 Would you like to comment on any of the answers you have given, or the questions you have been asked?
Would you like to remark on the investigation or express your own view on quality of life? If so, please feel free to write any comments, favorable or otherwise, below.

323-324 Did the questionnaire cover all the dimensions that relate to **your** quality of life?

1 yes 2 not sure 3 no

If you answered no or not sure, please state which topics have not been included:

SERVICE SATISFACTION SCALE-30

Service Satisfaction Scale (SSS-30) has been developed by Thomas K. Greenfield & C. Clifford Attkisson. Original instrument has been published in English. The purpose of this instrument is to assess a number of empirical facets of satisfaction with health, mental health, or substance abuse services. The SSS-30 is a 5-dimensional, generic measure of satisfaction for adults.

Abbreviated Name: SSS-30
Author(s): Thomas K. Greenfield & C. Clifford Attkisson
Purpose: To assess a number of empirical facets of satisfaction with health, mental health, or substance abuse services.
Population: Adult
Age Range : 18 and over
Type of Instrument: Satisfaction
Mode of Administration:

Rater:	Self-administered
Time required:	10-15 minutes
Response Options:	Likert scale
Scoring:	Global score
	Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 30
Original Language: English
Existing Translations : French, Italian

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Contact for information and permission to use:

Thomas K. Greenfield, Ph.D.
Senior Scientist & Director
National Alcohol Research Center
Alcohol Research Group
2000 Hearst Ave., Suite 300
Berkeley, CA 94709-2176 USA
FAX: (510) 642-7175
Email: tgreenfield@arg.org

Dimensions covered by the questionnaire :

- Manner and Skill
- Perceived Outcome
- Office Procedures
- Accessibility
- Waiting

Key References:

1. Greenfield, Thomas K. & Attkisson, C. Clifford. (1999). The UCSF Client Satisfaction Scales: II. The Service Satisfaction Scale-30. In Mark Maruish (Eds.), The Use of Psychological Testing for Treatment Planning & Outcome Assessment (pp. 1347-1367, Chapter 44). Mahwah, NJ: Lawrence Erlbaum Associates.
2. Attkisson, C. C., and Greenfield, T. K. (1994). The Client Satisfaction Questionnaire-8 and the Service Satisfaction Scale-30. In M. Maruish (Ed.) The use of Psychological Testing for Treatment Planning and Outcome Assessment, pp. 402-420. Hillsdale, NJ: Lawrence Erlbaum Associates

SERVICES EVALUATION (SSS-30 Practitioner Version)

SAMPLE AND SUBSCALE KEY *(USE ONLY WITH PERMISSION)*

Please read the following statements carefully. Indicate the answer that best describes your feeling about each aspect of the services you have received. We are interested in your *overall experience* based on all visits or contacts you have had *during the last year*. By "practitioner" we mean the one or more doctors, psychologists, counselors, clinicians, etc., who have worked with you.

What is your overall feeling about the . . .

M	1.	Kinds of services offered *DELIGHTED MOSTLY SATISFIED MIXED MOSTLY DISSATISFIED TERRIBLE **
M	2.	Opportunity to choose which practitioner you see *TERRIBLE MOSTLY DISSATISFIED MIXED MOSTLY SATISFIED DELIGHTED **
O	3.	Effect of services in helping you deal with your problems
P	4.	Office personnel (receptionists, clerks) on the telephone or in person
P	5.	Office procedures (scheduling, forms, tests, etc.)
M	6.	Professional knowledge and competence of the main practitioner(s)
A	7.	Location and accessibility of the services (distance, parking, public transportation, etc.)
	8.	Appearance and physical layout of the facility (e.g., waiting area)
M	9.	Ability of your practitioner(s) to listen to and understand your problems
M	10.	Personal manner of the main practitioner(s) seen
W	11.	Waiting time between asking to be seen and the appointment (date and time) given
W	12.	Waiting time when you come to be seen or keep an appointment made
A	13.	Availability of appointment times that fit your schedule
	14.	Cost of services to me
O	15.	Effect of services in maintaining well-being and preventing relapse
M	16.	Confidentiality and respect for your rights as an individual
O	17.	Amount of help you have received
O	18.	Availability of information on how to get the most out of the services
O	19.	Prescription (or nonprescription) of medications
M	20.	Explanations of specific procedures and approaches used
O	21.	Effect of services in helping relieve symptoms or reduce problems
A	22.	Response to crises or urgent needs during office hours
A	23.	Arrangements made for after hours emergencies or urgent help
M	24.	Thoroughness of the main practitioner(s) you have seen
O, P	25.	Appropriate use of referrals to other practitioners or services when needed
P	26.	Collaboration between service providers (if more than one)
	27.	Publicity or information about programs and services offered
P	28.	Handling and accuracy of your records (as best you can tell)
O	29.	Contribution of services to achievement of your life goals
M	30.	In an overall general sense, how satisfied are you with the service you have received?
	31.	(If applicable) Support of the group as a whole, helpfulness and caring of its members

SUBSCALE KEY

M = Manner and Skill (9-items; average alpha = .88)
O = Perceived Outcome (8-items; average alpha = .83)
P = Procedures (5-items; average alpha = .74)
A = Accessibility (4-items; average alpha = .67)
W = Waiting (2 items, may optionally be combined with Access)

*Example Item scale. Note that individual item scale anchors alternate direction throughout the instrument; scoring reverses every other item, allowing validity check for rote responding. For permission to use: tgreenfield@arg.org, fax +1=510-642-7175

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It is important to know something about our clients as a whole, so we request some demographic information. Only grouped data will be used, and you will never be identified. However, if you prefer not to answer any or all questions, you may freely do so.

32. About how many miles (one way) from the facility do you live?

☐ 5 or Less ☐ 6-10 ☐ 11-15 ☐ 16-20 ☐ 20-25 ☐ 26 or more

33. Approximately how many *weeks* have you been involved with this program?

☐ Less than 1 ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7-12 ☐ more than 12

34. Including today's, approximately how many sessions have you had in this program?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6-10 ☐ 11-20 ☐ 21-30 ☐ 31-50 ☐ 51+

35. Your Sex: MALE ☐ FEMALE ☐

36. Your Age:

☐ UNDER 20 ☐ 21-25 ☐ 26-35 ☐ 36-45 ☐ 46-55 ☐ 56-65 ☐ 66-75 ☐ 76-85 ☐ 86+

37. Yearly Family Income:

Under $10,000	☐	$10,000 - $20,000	☐
$20,001 - $40,000	☐	$40,001 - $60,000	☐
$60,001 - $80,000	☐	$80,000 - $100,000	☐
		$100,000 or more	☐

38. Your Education:

Grade 8 or less	☐	Some high school	☐
High school grad.	☐	Some college	☐
College grad.	☐	Some post grad.	☐
Masters	☐	Ph.D., M.D., etc.	☐

39. Ethnic Background:

Caucasian/White	☐	Asian/Pacific American	☐
Native American/Indian	☐	Hispanic/Latino	☐
African American/Black	☐	Other (Specify)	☐
Prefer not to answer	☐	_____	

40. In general these days, how do you feel about your life as a whole?

☐ TERRIBLE ☐ UNHAPPY ☐ MOSTLY DISSATISFIED ☐ MIXED ☐ MOSTLY SATISFIED ☐ PLEASED ☐ DELIGHTED

41. In general these days, how do you feel about your health?

☐ TERRIBLE ☐ UNHAPPY ☐ MOSTLY DISSATISFIED ☐ MIXED ☐ MOSTLY SATISFIED ☐ PLEASED ☐ DELIGHTED

THANK YOU VERY MUCH FOR YOUR HELP WITH THIS SURVEY. WE WOULD APPRECIATE ANY ADDITIONAL COMMENTS ABOUT THIS SERVICE YOU WOULD CARE TO ADD. YOU MAY WRITE THEM BELOW

42. The thing I have liked best about my experience here is:

43. What I liked least was:

44. If I could change one thing about this service it would be:

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SICKNESS IMPACT PROFILE

A 136-item self- or interviewer-administered, behaviorally-based, health status questionnaire. Everyday activities in 12 categories (sleep and rest, emotional behavior, body care and movement, home management, mobility, social interaction, ambulation, alertness behavior, communication, work, recreation and pastimes, and eating) are measured. Respondents "endorse" items that describe themselves and are related to their health. The SIP is scored according to the number and type of items endorsed. Scoring can be done at the level of categories and dimensions as well as at the total SIP level.

Abbreviated Name: SIP
Author(s): Betty Gilson & Marilyn Bergner
Purpose: To provide a descriptive profile of changes in a person's behavior due to sickness
Population: Adult
Age Range : 18 years and over
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-/ Interviewer-administered
Time required:	30 minutes
Response Options:	Check applicable items
Scoring:	Global score: Minimum score: 0 / Maximum score: 100 Scores by dimension
Score Direction:	Lower scores show better QoL
Weighting:	Yes

Number of Items: 136
Original Language: English
Existing Translations : Arabic, Chinese, Danish, Finnish, French, Dutch, German, Italian, Norwegian, Portuguese, Russian, Spanish, Swedish, Tamil, Thai

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Contact for information and permission to use:

Medical Outcomes Trust
235 Wyman Street, Suite 130
Waltham, MA 02451
USA
Phone: +1(617)-426-4046
Fax: +1(617)- 587-4232
Email: info@outcomes-trust.org

Elizabeth Skinner,
Health Policy & Management
Bloomberg School of Public Health
Johns Hopkins University
624 N. Broadway
Baltimore
Maryland 21205 USA
Phone: +1(410) 614-4022
Fax: +1(410) 955-0470
E-mail : askinner@jhsph.edu

Dimensions covered by the questionnaire :

- Physical dimension:
  body care and movement
  ambulation

mobility
- Psychosocial dimension:
  emotional behavior
  alertness behaviour
  social interaction
  communication
- Sleep and rest
- Eating
- Home management
- Work
- Recreation and pastimes

Key References:

1. Bergner M, Bobbitt RA, Carter WB, Gilson BS. The Sickness Impact Profile: development and final revision of a health status measure. Med Care. 1981 Aug;19(8):787-805.

The final development of the Sickness Impact Profile (SIP), a behaviorally based measure of health status, is presented. A large field trial on a random sample of prepaid group practice enrollees and smaller trials on samples of patients with hyperthyroidism, rheumatoid arthritis and hip replacements were undertaken to assess reliability and validity of the SIP and provide data for category and item analyses. Test-retest reliability (r = 0.92) and internal consistency (r - 0.94) were high. Convergent and discriminant validity was evaluated using the multitrait--multimethod technique. Clinical validity was assessed by determining the relationship between clinical measures of disease and the SIP scores. The relationship between the SIP and criterion measures were moderate to high and in the direction hypothesized. A technique for describing and assessing similarities and differences among groups was developed using profile and pattern analysis. The final SIP contains 136 items in 12 categories. Overall, category, and dimension scores may be calculated.

2. Carter WB, Bobbitt RA, Bergner M, Gilson BS. Validation of an interval scaling: the sickness impact profile. Health Serv Res. 1976 Winter;11(4):516-28.

The Sickness Impact Profile (SIP) is a measure of sickness-related behavioral dysfunction consisting of 189 items in 14 topic categories. To increase its discrimination, precision, and sensitivity in accounting for variance, the decision was made to scale the instrument. A two-step direct scaling procedure was used in order to avoid the monumental scaling tasks required by indirect procedures that guarantee equal-interval results; but because an equal-interval scale was needed, it was necessary to validate the scale values obtained and investigated the equal-intervval properties of the obtained scale. A three-stage validation process is described, consisting of an initial scaling by a group of 25 health professionals and students in 1973, a second scaling by 108 members of a prepaid group health plan in 1975, and an investigation of the metric properties of the resulting scale values. In addition, the concept of dysfunction underlying the SIP was validated. SIP scores from a field trial were compared with mean ratings of severity of dysfunction represented by the combinations of checked items from which the scores were derived.

3. Bergner M, Bobbitt RA, Kressel S, Pollard WE, Gilson BS, Morris JR. The sickness impact profile: conceptual formulation and methodology for the development of a health status measure. Int J Health Serv. 1976;6(3):393-415.

The development of a health status measure, the Sickness Impact Profile (SIP), is described in terms of both its conceptualization and methodology. The need for a health status measure that is sensitive and appropriate, based on sickness-related behavior, and culturally unbiased, is discussed. A model of sickness behavior is presented as a guide for methodological development. The description of the initial developmental stage of the SIP includeds detailed discussion and documentation of the collection, sorting and grouping of items that comprise the SIP, scaling of the items, scoring of the instrument, and testing and revision of the prototype instrument. Results of preliminary tests of reliability, validity, and administrative feasibility are presented. Subsequent steps in revision and finalization, now under way, are outlined.

4. Bergner M, Bobbitt RA, Pollard WE, Martin DP, Gilson BS. The sickness impact profile: validation of a health status measure. Med Care. 1976 Jan;14(1):57-67.

The Sickness Impact Profile (SIP), a measure of health status, is being developed as an outcome measure of health care. A preliminary study of the validity of the SIP was conducted on a sample of 278 subjects who were grouped into four subsamples differing in kind and severity of sickness. Selfassessment of health status, clinician assessment of health status, and other measures of dysfunction were used as criteria. SIP scores discriminated among subsamples, and correlations between criterion measures and SIP scores provided evidence for the validity of the SIP. Differences among the correlations obtained for each criterion measure with SIP score are discussed in terms of the need for the development of criterion measures that can be expected to differentially relate to the constructs inherent in the SIP.

5. Pollard WE, Bobbitt RA, Bergner M, Martin DP, Gilson BS. The Sickness Impact Profile: reliability of a health status measure. Med Care. 1976 Feb;14(2):146-55.

This report describes the results of research conducted on the reliability of the Sickness Impact Profile (SIP). The SIP is a questionnaire instrument designed to measure sickness-related behavioral dysfunction and is being developed for use as an outcome measure in the evaluation of health care. The test-retest reliability of the SIP in terms of several reliability measures was investigated using different interviewers, forms, administration procedures, and a variety of subjects who differed in terms of type and severity of dysfunction. The results provided evidence for the feasibility of collecting reliable data using the SIP under these various conditions. In addition, subject variability in relation to reliability is discussed.

6. Gilson BS, Gilson JS, Bergner M, Bobbit RA, Kressel S, Pollard WE, Vesselago M. The sickness impact profile. Development of an outcome measure of health care. Am J Public Health. 1975 Dec;65(12):1304-10.

7. Lipsett PA, Swoboda SM, Campbell KA, et al. Sickness Impact Profile Score versus a Modified Short-Form survey for functional outcome assessment: acceptability, reliability, and validity in critically ill patients with prolonged intensive care unit stays. J Trauma. 2000 Oct;49(4):737-43.

Background: Quality of life after surgical critical illness is an important measure of outcome. The Sickness Impact Profile Score (SIP) has been validated in critically ill patients, but the Modified Short-Form (MSF) has not been directly compared with it. Methods: The SIP and MSF-36 were coadministered to 127 patients (surrogates) with a prolonged surgical critical illness at baseline at 1, 3, 6, and 12 months. Reliability, validity, and acceptability were determined for overall and subscores at each time point. Results: The overall SIP and eight subscores, including physical health and psychosocial health, were all significantly improved at 1 year compared with baseline ($p < 0.05$). However, the MSF-36 was improved only in health perception ($p < 0.05$), but pain scores were higher ($p < 0.05$) than at baseline. Internal consistency of the MSF-36 was poor at 1 and 3 months. Correlation between the tools was excellent at baseline and 1 year but variable in overall and subscores at other time points. Conclusion: The SIP is more comprehensive, reliable, and acceptable in determining specific quality-of-life abnormalities, but the MSF-36 is easier to administer and correlates well at baseline and 1 year in patients with a prolonged critical illness.

8. van Straten A, de Haan RJ, Limburg M, et al. A stroke-adapted 30-item version of the Sickness Impact Profile to assess quality of life (SA-SIP30). Stroke. 1997 Nov;28(11):2155-61.

Background and Purpose: In view of the growing therapeutic options in stroke, measurement of quality of life has become increasingly relevant as an outcome parameters. The Sickness Impact Profile (SIP) is one of the most widely used measures to assess quality of life. To overcome the major disadvantage of the SIP, its length, we constructed a short stroke adapted 30-item SIP version (SA-SIP30). Methods: Data on the original SIP version were collected for 319 communicative patients at 6 months after stroke. The 12 subscales and the 136 items of the original SIP were reduced to 8 subscales with 30 items in a three step procedure, on the basis of relevancy and homogeneity. Reliability of the SA-SIP30 was evaluated by means of an analysis of homogeneity (Cronbach's alpha coefficient). Different types of validity were assessed:

construct, clinical, and external validities. Results: Homogeneity of the SA-SIP30 was demonstrated by a high Cronbach's alpha (0.85). Principal component analyses revealed the same two dimensions as in the original SIP (a physical and a psychosocial dimension). The SA-SIP30 could explain 91% of the variation in scores of the original SIP in the same cohort of patients, and 89% in a different cohort. Furthermore, the SA-SIP30 was related to other functional health measures similar to how the original SIP was. We could demonstrate that the SA-SIP30 was able to distinguish patients with lacunar infarctions from patients with cortical or subcortical lesions. Conclusions: We conclude that the SA-SIP30 is a feasible and clinimetrically sound measure to assess quality of life after stroke.

9. de Bruin AF, Buys M, de Witte LP, Diederiks JP. The sickness impact profile: SIP68, a short generic version. First evaluation of the reliability and reproducibility. J Clin Epidemiol. 1994 Aug;47(8):863-71.

In previous research a short version of the Sickness Impact Profile (SIP136) was developed, containing 68 items. This SIP68 is intended as a short generic alternative to the original SIP. High reliability of the SIP68 was reported when it was extracted from the SIP136. This paper is a report on the first reliability testing of the SIP68 administered as an independent instrument without the context of the SIP136. To establish the test-retest reliability and the internal consistency of the new instrument, 51 patients of an outpatient department of rheumatology completed the SIP68 twice, with an interval of 48 hours. To compare the performance of the independent SIP68 with the SIP68 extracted from the SIP136, the SIP136 also was completed two times by the same 51 respondents. Test-retest reliability for both administration types was assessed by means of the intraclass correlation coefficient and the Jaccard's similarity ratio. Internal consistency was assessed by means of Cronbach's alpha. The reliability appears to be high in both the independent SIP68 as well as the extracted SIP68. Moreover, the reliability of the independent SIP68 appears to be as high as for the SIP136. These findings were very encouraging, indicating that the SIP68 may very well serve as a generic alternative to the SIP136.

10. de Bruin AF, Diederiks JP, de Witte LP, Stevens FC, Philipsen H. The development of a short generic version of the Sickness Impact Profile. J Clin Epidemiol. 1994 Apr;47(4):407-18.

This study concerns the development of a short version of a well-known and much used clinimetric instrument called the Sickness Impact Profile (SIP). The SIP is a generic measure of functional status. Based on findings of a principal components analysis of over 800 SIPs from a multi-diagnostic population, a selection of 68 items divided over 6 dimensions was made and initially tested. As no support was found for the statistical validity of the categorical structure of the original SIP, a new structure, discovered through principal components analysis, was used as the basis for selecting items. Comparison of the scores on the selection with information provided by the original SIP showed very promising results: the 68 item selection may serve as a valid short SIP-version.

11. Sullivan M, Ahlmen M, Bjelle A, Karlsson J. Health status assessment in rheumatoid arthritis. II. Evaluation of a modified Shorter Sickness Impact Profile. J Rheumatol. 1993 Sep;20(9):1500-7.

Objective. To develop a shortened form of the Sickness Impact Profile (SIP) for routine practice. Methods. We used data from a study of health status in 99 women with rheumatoid arthritis (RA). A stepwise analysis model used physical discomfort (global rating), self-assessed pain (Body Symptom Scale), mental well-being (Mood Adjective Check List) and joint function (Keitel Index) to define important aspects of health. Results. Short forms of the SIP for discrimination (53 items), evaluation (25 items) and prediction (28 items) compared well in validity to the original 136-item SIP. The discriminative short form showed excellent reliability (internal consistency), matching the level of the generic SIP. The evaluative and predictive short forms had acceptable but lower internal consistency than the original Profile. Conclusion. We suggest a 64-item core health status questionnaire (SIP-RA) to be included and further tested in the arsenal of routine measurements in outpatients with RA. The questionnaire should include physical (Body care and movement, Mobility), psychosocial (Emotional behavior, Social interaction, Alertness behavior, Communication) and free-standing (Sleep and rest, Home management, Recreation and past-times, Eating) SIP categories, and it will improve the description of patients with RA.

Sickness

Impact

Profile[tm]

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SIP - 10030
SD I - 03564
SD II – 03657

THE FOLLOWING INSTRUCTIONS ARE FOR THE INTERVIEWER-ADMINISTERED QUESTIONNAIRE

INSTRUCTIONS TO BE READ TO THE RESPONDENT

Before beginning the questionnaire, I am going to read you the instructions.

You have certain activities that you do in carrying on your life. Sometimes you do all of these activities. Other times, because of your state of health, you don't do these activities in the usual way: you may cut some out; you may do some for shorter lengths of time; you may do some in different ways. These changes in your activities might be recent or longstanding. We are interested in learning about any changes that describe you today and are related to your state of health.

I will be reading statements that people have told us describe them when they are not completely well. Whether or not you consider yourself sick, there may be some statements that will stand out because they describe you today and are related to your state of health. As I read the questionnaire, think of yourself today. I will pause briefly after each statement. When you hear one that does describe you and is related to health please tell me and I will check it.

Let me give you an example. I might read the statement "I am not driving my car." If this statement is related to your health and describes you today, you should tell me. Also, if you have not been driving for some time because of your health, and are still not driving today, you should respond to this statement.

If you are in the hospital today, you are here because of your state of health, and you are not doing a number of the things you usually do. For instance, if driving is usual for you, then you are not driving today because you are in the hospital, and you should respond to this statement.

On the other hand, if you never drive or are not driving today because your car is being repaired, the statement, "I am not driving my car" is not related to your health and you should not respond to it. If you simply are driving less, or are driving shorter distances, and feel that the statement only partially describes you, please do not respond to it.

I am now going to begin the questionnaire. Please tell me if you want me to slow down, repeat a statement, or stop so that you can think about one. Also let me know any time you would like to review the instructions. Remember we are interested in the recent or longstanding changes in your activities that are related to your health.

THE FOLLOWING INSTRUCTIONS ARE FOR THE SELF-ADMINISTERED QUESTIONNAIRE

PLEASE READ THE ENTIRE INTRODUCTION BEFORE YOU READ THE QUESTIONNAIRE. IT IS VERY IMPORTANT THAT EVERYONE TAKING THE QUESTIONNAIRE FOLLOWS THE SAME INSTRUCTIONS.

You have certain activities that you do in carrying on your life. Sometimes you do all of these activities. Other times, because of your state of health, you don't do these activities in the usual way: you may cut some out; you may do some for shorter lengths of time; you may do some in different ways. These changes in your activities might be recent or longstanding. We are interested in learning about any changes that describe you today and are related to your state of health.

The questionnaire booklet lists statements that people have told us describe them when they are not completely well. Whether or not you consider yourself sick, there may be some statements that will stand out because they describe you today and are related to your state of health. As you read the questionnaire, think of yourself today. When you read a statement that you are sure describes you and is related to your health, place a check on the line to the right of the statement. For example:

I am not driving my car (031)

If you have not been driving for some time because of your health, and are still not driving today, you should respond to this statement.

On the other hand, if you never drive or are not driving today because your car is being repaired, the statement, "I am not driving my car" is not related to your health and you should not check it. If you simply are driving less, or are driving shorter distances, and feel that the statement only partially describes you, do not check it. In all of these cases you would leave the line to the right of the statement blank. For example:

I am not driving my car _____ (031)

Remember that we want you to check this statement only if you are sure it describes you today and is related to your state of health.

Read the introduction to each group of statements and then consider the statements in the order listed. While some of the statements may not apply to you, we ask that you please read all of them. Check those that describe you as you go along. Some of the statements will differ only in a few words, so please read each one carefully. While you may go back and change a response, your first answer is usually the best. Please do not read ahead in the booklet

Once you have started the questionnaire, it is very important that you complete it within one day (24 hours).

If you find it hard to keep your mind on the statements, take a short break and then continue. When you have read all of the statements on a page, put a check in the BOX in the lower right-hand corner. If you have any questions, please refer back to these instructions.

Please do not discuss the statements with anyone, including family members, while doing the questionnaire.

Now turn to the questionnaire booklet and read the statements. Remember we are interested in the recent or longstanding changes in your activities that are related to your health.

(SR-0499)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1.	I spend much of the day lying down in order to rest	_____	(083)
2.	I sit during much of the day	_____	(049)
3.	I am sleeping or dozing most of the time - day and night	_____	(104)
4.	I lie down more often during the day in order to rest	_____	(058)
5.	I sit around half-asleep	_____	(084)
6.	I sleep less at night, for example, wake up too early, don't fall asleep for a long time, awaken frequently	_____	(061)
7.	I sleep or nap more during the day	_____	(060)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(EB-0705)

PLEASE RESPOND TO (CHECK) <u>ONLY</u> THOSE STATEMENTS THAT YOU ARE <u>SURE</u> DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

_____ -_____

	I say how bad or useless I am, for example, that I am a burden on others	_____	(087)
2.	I laugh or cry suddenly	_____	(068)
3.	I often moan and groan in pain or discomfort	_____	(069)
4.	I have attempted suicide	_____	(132)
5.	I act nervous or restless	_____	(046)
6.	I keep rubbing or holding areas of my body that hurt or are uncomfortable	_____	(062)
7.	I act irritable and impatient with myself, for example, talk badly about myself, swear at myself, blame myself for things that happen	_____	(078)
8.	I talk about the future in a hopeless way	_____	(089)
9.	I get sudden frights	_____	(074)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(BCM-2003)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

_____ -_____

1.	I make difficult moves with help, for example, getting into or out of cars, bathtubs	_____	(084)
2.	I do not move into or out of bed or chair by myself but am moved by a person or mechanical aid	_____	(121)
3.	I stand only for short periods of time	_____	(072)
4.	I do not maintain balance	_____	(098)
5.	I move my hands or fingers with some limitation or difficulty	_____	(064)
6.	I stand up only with someone's help	_____	(100)
7.	I kneel, stoop, or bend down only by holding on to something	_____	(064)
8.	I am in a restricted position all the time	_____	(125)
9.	I am very clumsy in body movements	_____	(058)
10.	I get in and out of bed or chairs by grasping something for support or using a cane or walker	_____	(082)
11.	I stay lying down most of the time	_____	(113)
12.	I change position frequently	_____	(030)
13.	I hold on to something to move myself around in bed	_____	(086)

(Continued on next page)

(Continued from previous page)

14.	I do not bathe myself completely, for example, require assistance with bathing	_____	(089)
15.	I do not bathe myself at all, but am bathed by someone else	_____	(115)
16.	I use bedpan with assistance	_____	(114)
17.	I have trouble getting shoes, socks, or stockings on	_____	(057)
18.	I do not have control of my bladder	_____	(124)
19.	I do not fasten my clothing, for example, require assistance with buttons, zippers, shoelaces	_____	(074)
20.	I spend most of the time partly undressed or in pajamas	_____	(074)
21.	I do not have control of my bowels	_____	(128)
22.	I dress myself, but do so very slowly	_____	(043)
23.	I get dressed only with someone's help	_____	(088)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(HM-0668)

THIS GROUP OF STATEMENTS HAS TO DO WITH ANY WORK YOU USUALLY DO IN CARING FOR YOUR HOME OR YARD. CONSIDERING JUST THOSE THINGS THAT YOU DO, PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH

_____ -_____

1.	I do work around the house only for short periods of time or rest often	_____	(054)
2.	I am doing less of the regular daily work around the house than I would usually do	_____	(044)
3.	I am not doing any of the regular daily work around the house that I would usually do	_____	(086)
4.	I am not doing any of the maintenance or repair work that I would usually do in my home or yard	_____	(062)
5.	I am not doing any of the shopping that I would usually do	_____	(071)
6.	I am not doing any of the house cleaning that I would usually do	_____	(077)
7.	I have difficulty doing handwork, for example, turning faucets, using kitchen gadgets, sewing, carpentry	_____	(069)
8.	I am not doing any of the clothes washing that I would usually do	_____	(077)
9.	I am not doing heavy work around the house	_____	(044)
10.	I have given up taking care of personal or household business affairs, for example, paying bills, banking, working on budget	_____	(084)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(M-0719)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

_____
_

1.	I am getting around only within one building	_____	(086)
2.	I stay within one room	_____	(106)
3.	I am staying in bed more	_____	(081)
4.	I am staying in bed most of the time	_____	(109)
5.	I am not now using public transportation	_____	(041)
6.	I stay home most of the time	_____	(066)
7.	I am only going to places with restrooms nearby	_____	(056)
8.	I am not going into town	_____	(048)
9.	I stay away from home only for brief periods of time	_____	(054)
10.	I do not get around in the dark or in unlit places without someone's help	_____	(072)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(SI-1450)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1.	I am going out less to visit people	_____	(044)
2.	I am not going out to visit people at all	_____	(101)
3.	I show less interest in other people's problems, for example, don't listen when they tell me about their problems, don't offer to help	_____	(067)
4.	I often act irritable toward those around me, for example, snap at people, give sharp answers, criticize easily	_____	(084)
5.	I show less affection	_____	(052)
6.	I am doing fewer social activities with groups of people	_____	(036)
7.	I am cutting down the length of visits with friends	_____	(043)
8.	I am avoiding social visits from others	_____	(080)
9.	My sexual activity is decreased	_____	(051)
10.	I often express concern over what might be happening to my health	_____	(052)
11.	I talk less with those around me	_____	(056)
12.	I make many demands, for example, insist that people do things for me, tell them how to do things	_____	(088)
13.	I stay alone much of the time	_____	(086)

(Continued on next page)

(Continued from previous page)

14.	I act disagreeable to family members, for example, I act spiteful, I am stubborn	_____	(088)
15.	I have frequent outbursts of anger at family members, for example, strike at them, scream, throw things at them	_____	(119)
16.	I isolate myself as much as I can from the rest of the family	_____	(102)
17.	I am paying less attention to the children	_____	(064)
18.	I refuse contact with family members, for example, turn away from them	_____	(115)
19.	I am not doing the things I usually do to take care of my children or family	_____	(079)
20.	I am not joking with family members as I usually do	_____	(043)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(A-0842)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1.	I walk shorter distances or stop to rest often	_____	(048)
2.	I do not walk up or down hills	_____	(056)
3.	I use stairs only with mechanical support, for example, handrail, cane, crutches	_____	(067)
4.	I walk up or down stairs only with assistance from someone else	_____	(076)
5.	I get around in a wheelchair	_____	(096)
6.	I do not walk at all	_____	(105)
7.	I walk by myself but with some difficulty, for example, limp, wobble, stumble, have stiff leg	_____	(055)
8.	I walk only with help from someone	_____	(088)
9.	I go up and down stairs more slowly, for example, one step at a time, stop often	_____	(054)
10.	I do not use stairs at all	_____	(083)
11.	I get around only by using a walker, crutches, cane, walls, or furniture	_____	(079)
12.	I walk more slowly	_____	(035)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(AB-0777)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1.	I am confused and start several actions at a time	_____	(090)
2.	I have more minor accidents, for example, drop things, trip and fall, bump into things	_____	(075)
3.	I react slowly to things that are said or done	_____	(059)
4.	I do not finish things I start	_____	(067)
5.	I have difficulty reasoning and solving problems, for example, making plans, making decisions, learning new things	_____	(084)
6.	I sometimes behave as if I were confused or disoriented in place or time, for example, where I am, who is around, directions, what day it is	_____	(113)
7.	I forget a lot, for example, things that happened recently, where I put things, appointments	_____	(078)
8.	I do not keep my attention on any activity for long	_____	(067)
9.	I make more mistakes than usual	_____	(064)
10.	I have difficulty doing activities involving concentration and thinking	_____	(080)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(C-0725)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1.	I am having trouble writing or typing	_____	(070)
2.	I communicate mostly by gestures, for example, moving head, pointing, sign language	_____	(102)
3.	My speech is understood only by a few people who know me well	_____	(093)
4.	I often lose control of my voice when I talk, for example, my voice gets louder or softer, trembles, changes unexpectedly	_____	(083)
5.	I don't write except to sign my name	_____	(083)
6.	I carry on a conversation only when very close to the other person or looking at him	_____	(067)
7.	I have difficulty speaking, for example, get stuck, stutter, stammer, slur my words	_____	(076)
8.	I am understood with difficulty	_____	(087)
9.	I do not speak clearly when I am under stress	_____	(064)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

THE NEXT GROUP OF STATEMENTS HAS TO DO WITH ANY WORK YOU USUALLY DO OTHER THAN MANAGING YOUR HOME. BY THIS WE MEAN ANYTHING THAT YOU REGARD AS WORK THAT YOU DO ON A REGULAR BASIS.

DO YOU USUALLY DO WORK OTHER THAN MANAGING YOUR HOME?

_____ YES _____ NO

IF YOU ANSWERED YES, GO ON TO THE NEXT PAGE.

IF YOU ANSWERED NO:

ARE YOU RETIRED?

_____ YES _____ NO

IF YOU ARE RETIRED, WAS YOUR RETIREMENT RELATED TO YOUR HEALTH?

_____ YES _____ NO

IF YOU ARE NOT RETIRED, BUT ARE NOT WORKING, IS THIS RELATED TO YOUR HEALTH?

_____ YES _____ NO

NOW SKIP THE NEXT PAGE.

(W-0515)

IF YOU ARE NOT WORKING AND IT IS NOT BECAUSE OF YOUR HEALTH, PLEASE SKIP THIS PAGE.

NOW CONSIDER THE WORK YOU DO AND RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH. (IF TODAY IS A SATURDAY OR SUNDAY OR SOME OTHER DAY THAT YOU WOULD USUALLY HAVE OFF, PLEASE RESPOND AS IF TODAY WERE A WORKING DAY.)

_____
_

1. I am not working at all _____ (361)

(IF YOU CHECKED THIS STATEMENT, SKIP TO THE NEXT PAGE.)

2. I am doing part of my job at home _____ (037)
3. I am not accomplishing as much as usual at work _____ (055)
4. I often act irritable toward my work associates, for example, snap at them, give sharp answers, criticize easily _____ (080)
5. I am working shorter hours _____ (043)
6. I am doing only light work _____ (050)
7. I work only for short periods of time or take frequent rests _____ (061)
8. I am working at my usual job but with some changes, for example, using different tools or special aids, trading some tasks with other workers _____ (034)
9. I do not do my job as carefully and accurately as usual _____ (062)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(RP-0422)

THIS GROUP OF STATEMENTS HAS TO DO WITH ACTIVITIES YOU USUALLY DO IN YOUR FREE TIME. THESE ACTIVITIES ARE THINGS THAT YOU MIGHT DO FOR RELAXATION, TO PASS THE TIME, OR FOR ENTERTAINMENT. PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1.	I do my hobbies and recreation for shorter periods of time	_____	(039)
2.	I am going out for entertainment less often	_____	(036)
3.	I am cutting down on some of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading	_____	(059)
4.	I am not doing any of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading	_____	(084)
5.	I am doing more inactive pastimes in place of my other usual activities	_____	(051)
6.	I am doing fewer community activities	_____	(033)
7.	I am cutting down on some of my usual physical recreation or activities	_____	(043)
8.	I am not doing any of my usual physical recreation or activities	_____	(077)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(E-0705)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1.	I am eating much less than usual	_____	(037)
2.	I feed myself but only by using specially prepared food or utensils	_____	(077)
3.	I am eating special or different food, for example, soft food, bland diet, low-salt, low-fat, low-sugar	_____	(043)
4.	I eat no food at all but am taking fluids	_____	(104)
5.	I just pick or nibble at my food	_____	(059)
6.	I am drinking less fluids	_____	(036)
7.	I feed myself with help from someone else	_____	(099)
8.	I do not feed myself at all, but must be fed	_____	(117)
9.	I am eating no food at all, nutrition is taken through tubes or intravenous fluids	_____	(133)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

NOW, PLEASE REVIEW THE QUESTIONNAIRE TO BE CERTAIN YOU HAVE FILLED OUT ALL THE INFORMATION. LOOK OVER THE BOXES ON EACH PAGE TO MAKE SURE EACH ONE IS CHECKED SHOWING THAT YOU HAVE READ ALL OF THE STATEMENTS. IF YOU FIND A BOX WITHOUT A CHECK, THEN READ THE STATEMENTS ON THAT PAGE.

CALCULATION OF CATEGORY SCORES, DIMENSION SCORES, AND OVERALL SIP SCORE

The score for each category is calculated by adding the scale values for each item checked within the category and dividing by the maximum possible dysfunction score for the category. This figure is then multiplied by 100 to obtain the category score.

Two dimension scores may be calculated. The physical dimension score is obtained by adding the scale values for each item checked within categories BCM, M, and A, dividing by the maximum possible dysfunction score for these categories, and then multiplying by 100; the psychosocial dimension score is obtained by adding the scale values for each item checked within categories EB, SI, AB, and C, dividing by the maximum possible dysfunction score for these categories, and then multiplying by 100. The scores for the remaining categories are always calculated individually.

The overall score for the SIP is calculated by adding the scale values for each item checked across all categories and dividing by the maximum possible dysfunction score for the SIP. This figure is then multiplied by 100 to obtain the SIP overall score.

In the SIP booklet the scale values are coded to one decimal as follows:

1. Following the checking line for each item, the item number and scale value are shown, e.g., 070-083 indicates item 70 has a scale value of 8.3.

2. Following each category code in the upper right-hand corner of the page, the total possible scale value for the category is shown, e.g., SR-0499 indicates a total possible scale value of 49.9 for category SR.

3. On the title page of the booklet in the lower right-hand corner appears SD I-03564 and SD II-03657. These indicate a total possible scale value of 356.4 for the physical scoring dimension, and total scale value of 365.7 for the psychosocial scoring dimension. These are the denominators for calculating the respective dimension scores.

4. Also on the title page of the booklet in the lower right-hand corner appears SIP-10030 indicating a total possible scale value of 1003.0 for the entire SIP. This is the denominator for calculating the overall SIP score.

Please note that there are two special considerations in scoring Category W - Work:

(1) When a subject answers YES to either,

"If you are retired, was your retirement related to your health?" or

"If you are not retired, but are not working, is this related to your health?",

he is instructed to skip Category W - Work. However, in editing the questionnaire prior to coding or scoring, for subjects who answered YES to either of these questions, item 100 should be checked.

(2) Item 100, the first item, has been coded 100-361, indicating an unusually high scale value. The scale value for this item has been statistically adjusted to take into account the fact that when item 100 is checked no other item in category W can be checked.

SILVER LINING QUESTIONNAIRE

The Silver Lining Questionnaire measures the extent to which people believe their illness has had a positive benefit despite the negative consequences of being ill. Research suggests that this positive interpretation is not due to a form of self-delusion but instead reflects personal growth and that it can be enhanced by the context. Its role in recovery from illness is complex.

Abbreviated Name: SLQ
Author(s): Samantha C. Sodergren & Michael Hyland
Purpose: To assess the positive experiences of illness
Population: Adult
Age Range : 18 to 90 years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-administered
Time required:	5 minutes
Response Options:	Likert scale
Scoring:	Global score: Minimum score: 0 / Maximum score: 38
Score Direction:	Higher scores show better QoL

Number of Items: 38
Original Language: English

Contact for information and permission to use:

Professor Michael E. Hyland
Department of Psychology
University of Plymouth
Drake Circus
Plymouth, Devon, PL4 8AA UK
Phone: +44 1752 233157 (secretary) / 233144 (direct)
Fax: +44 1752 233176
Email: mhyland@plymouth.ac.uk

Dimensions covered by the questionnaire :

- Uni-dimensional assessing overall positivity in illness

Key References:

1. Sodergren SC, Hyland ME. Qualitative phase in the development of the Silver Lining Questionnaire. Quality of Life Research, 1997; 6 (7-8): 365.
2. Sodergren SC, Hyland ME. What are the positive consequences of illness? Psychology and Health 2000; 15: 85-97.

The Silver Lining Questionnaire

What is this questionnaire all about?

Although illness can be a distressing experience, some people who have or have had an illness talk about its positive aspects. This questionnaire asks you to think about this positive side of illness.

How do I complete this questionnaire?

On the next two pages, there are 38 statements about the experience of being ill. Please indicate the extent to which you agree or disagree with each statement by circling a number between 5 "strongly agree" and 1 "strongly disagree". There are no right or wrong answers, your own personal views are important.

An example to help you:

I appreciate other people more because of my illness	strongly agree	agree	not sure	disagree	strongly disagree
	(5)	4	3	2	1

If you strongly feel that you appreciate other people more now as a result of your illness, you would circle the number five.

Please complete: **Age** …….

Sex (tick) Male ☐

Female ☐

Please write any illnesses you have

……..

Please circle *one* number for *each* statement

	strongly agree	**agree**	**not sure**	**disagree**	**strongly disagree**
1. I appreciate life more because of my illness	5	4	3	2	1
2. My illness gave me a new start in life	5	4	3	2	1
3. My life is much better now than it was before	5	4	3	2	1
4. My illness has made me live life to its fullest	5	4	3	2	1
5. Because of my illness I find it easier to accept what life has in store	5	4	3	2	1
6. My illness made me think about the true purpose of life	5	4	3	2	1
7. My religious/spiritual beliefs deepened because of my illness	5	4	3	2	1
8. I am now more open to other religions because of my illness	5	4	3	2	1
9. My illness made me a better person	5	4	3	2	1
10. I became a happier person because of my illness	5	4	3	2	1
11. I am a calmer person because of my illness	5	4	3	2	1
12. My illness made me more mature	5	4	3	2	1
13. My illness made me a more tolerant person	5	4	3	2	1
14. My illness made me realise that I matter as a person	5	4	3	2	1
15. My illness gave me more confidence	5	4	3	2	1
16. I am less concerned about failure because of my illness	5	4	3	2	1
17. My illness gave me permission to do things for myself	5	4	3	2	1
18. My illness made me a more determined person	5	4	3	2	1
19. My illness helped me find myself	5	4	3	2	1
20. My illness made me more aware of my strengths	5	4	3	2	1
21. Through my illness I discovered a talent I didn't know I had	5	4	3	2	1
22. I can face whatever is around the corner because of my illness	5	4	3	2	1

Please turn over

Please circle *one* number for *each* statement

	strongly agree	**agree**	**not sure**	**disagree**	**strongly disagree**
23. My illness encouraged me to reflect on how I feel about myself.	5	4	3	2	1
24. My illness made me face up to problem areas of my life	5	4	3	2	1
25. My illness strengthened my relationships with others	5	4	3	2	1
26. My illness made me less concerned with the approval of others	5	4	3	2	1
27. Because of my illness I have more to offer other people	5	4	3	2	1
28. My illness made me more at ease with others	5	4	3	2	1
29. I see others in their true colours because of my illness	5	4	3	2	1
30. My illness gave me the opportunity to meet new people	5	4	3	2	1
31. My illness taught me how to stand up for myself	5	4	3	2	1
32. My illness made me put an end to troublesome relationships	5	4	3	2	1
33. My illness made me less judgmental of others	5	4	3	2	1
34. I have been an inspiration to others	5	4	3	2	1
35. People can be more open with me since my illness	5	4	3	2	1
36. My illness changed other people for the better	5	4	3	2	1
37. My illness changed other people's perception of me for better	5	4	3	2	1
38. Other people appreciate me more because of my illness	5	4	3	2	1

Thank you for completing this questionnaire

SOCIAL ADJUSTMENT SCALE - SELF REPORT

The Social Adjustment Scale–Self-Report (SAS-SR) evaluates the efficacy of pharmacological treatments of mental disorders to provide an understanding of a client's satisfaction with his or her social situation.

Both instrumental (what we do in the world) and expressive (how we relate to others) aspects of role performance are evaluated.

The SAS–SR assessment can be used by psychiatrists, psychologists, social workers, and other mental health professionals in clinical or research settings. Results are useful for treatment planning, as well as for monitoring progress.

Abbreviated Name: SAS-SR
Author(s): Myrna M Weissman
Purpose: To measure the level of both behavioral and emotional social adjustment across six major areas
Population: Adult
Age Range: 17 and over
Type of Instrument: Social-Functioning
Mode of Administration:

Rater:	Self-administered
Time required:	20-30 minutes
Response Options:	5-point Likert scale
Scoring:	Global score
	Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 54; Short version 24 and Screener 14
Original Language: English
Existing Translations: Afrikaans, Cantonese for China, Czech, Danish, Dutch, Finnish, French, German, Greek, Hebrew, Hungarian, Italian, Mandarin for China, Norwegian, Portuguese, Russian, Spanish, Swedish

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Fax: 1-888-540-4484
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Dimensions covered by the questionnaire :

- Work (paid or unpaid)
- Social and leisure activities
- Relationships with extended family
- Role as marital partner
- Parental role
- Role within family unit (including perceptions about economic functioning)

Key References:

1. Weissman MM, Bothwell S. Assessment of social adjustment by patient self-report. Arch Gen Psychiatry. 1976 Sep;33(9):1111-5.

Current emphasis on early case finding, outpatient care, and on longitudinal studies of asymptomatic patients has focused attention on the community adjustment of psychiatric patients. Thus, simple and inexpensive methods such as self-report scales, which allow the routine assessment of patient adjustment, are potentially useful. The derivation and testing of such a method, the Social Adjustment Scale Self-Report, is described. This scale covers the patient's role performance, interpersonal relationships, friction, feelings and satisfaction in work, and social and leisure activities with the extended family, as a spouse, parent, and member of a family unit. Self-report results based on 76 depressed outpatients were comparable to those obtained from relatives as well as by a rater who interviewed the patient directly.

2. Weissman MM, Prusoff BA, Thompson WD, Harding PS, Myers JK. Social adjustment by self-report in a community sample and in psychiatric outpatients. J Nerv Ment Dis. 1978 May;166(5):317-26.

Data are presented on social functioning derived from a self-report social adjustment scale (SAS-SR) administered to 774 subjects including a community sample and three psychiatric outpatient populations: acute depressives, alcoholics, and schizophrenics. This self-report scale derives from an interview form and was developed and tested on depressed outpatients. Since its publication, it has been used in populations other than depressives including other psychiatric patients, nonpsychiatric patients, and nonpatients. The purpose of this paper is to make data available to other investigators on results of this self-report social adjustment scale in a broad range of subjects and to describe further the psychometric properties, limitations, and utility of the scale. Findings show that the scale has wide applicability in a range of subjects but that certain cautions should be followed in using it with chronically impaired psychiatric populations who may not be involved in the major roles assessed by the scale.

SOCIAL ADJUSTMENT SELF REPORT QUESTIONNAIRE[2]

Sample Items

We are interested in finding out how you have been doing in the last two weeks. We would like you to answer some questions about your work, your spare time and your family life. There is no right or wrong answers to these questions.

Circle the Number of the answer you choose.

54. Have you had enough money to take care or your own and your immediate family's financial needs during the last 2 weeks?

1- I had enough money for needs.
2- I usually had enough money with minor problems.
3- About half the time I did not have enough money but did not have to borrow money.
4- I usually did not have enough money and had to borrow from others.
5- I had great financial difficulty.

19. How many friends have you seen or been in contact with (e.g., on the phone, via e-mail, etc.) in the last 2 weeks?

1- Nine or more friends.
2- Five to eight friends.
3- Two to four friends.
4- One friend.
5- No friends.

20. Have you been able to talk about your feelings and problems with one of your friends during the last 2 weeks?

1- I was always able to talk about my innermost feelings.
2- I was usually able to talk about my feelings.
3- About half the time I was able to talk about my feelings.
4- I was not usually able to talk about my feelings.
5- I was never able to talk about my feelings.
6- No applicable; I have no friends.

[2] Copyright ©1999 Multi-Health Systems Inc. All rights reserved. In the USA, P.O. Box 950, North Tonawanda, NY 14120-0950, 1-800-456-3003. In Canada, 3770 Victoria Park Ave., Toronto, ON M2H 3M6, 1-800-268-6011. Internationally, +1-416-492-2627. Fax, +1-416-492-3343. Reproduced with permission.

21. How many times in the last 2 weeks have you gone out socially with other people ? For example, visited friends, gone to movies, bowling, church, restaurants, or invited friends to your home ?

1- More than three times.
2- Three times.
3- Twice.
4- Once.
5- None.

22. How much time have you spent on hobbies or spare-time interests during the last 2 weeks? For example, have you been gardening, playing sports, listening to music, reading, or using the computer?

1- I spent most of my spare time on hobbies every day.
2- I spent some spare time on hobbies some of the days.
3- I spent a little spare time on hobbies.
4- I did not usually spend any time on hobbies but did watch TV.
5- I did not spend any spare time on hobbies or watching TV.

23. Have you had open arguments with your friends in the last 2 weeks?

1- I had no arguments and got along very well.
2- I usually got along well but had minor arguments.
3- I had more than one argument.
4- I had many arguments.
5- I was constantly in arguments.
6- Not applicable; I have no friends.[3]

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STRUCTURED INTERVIEW FOR SYMPTOMS AND CONCERNS

Structured Interview for Symtoms and Concerns (SISC) has been developed by Keith G. Wilson et al. Original instrument has been published in English. The purpose of this instrument is to assess the common symptoms and concerns of patients who are approaching to the ends of their lives. The SISC a 2-dimensional (Pain and symptoms assessment and End of life concerns), generic measure of quality of life for adults.

Abbreviated Name: SISC
Author(s): Keith G. Wilson, Ian D. Graham, Raymond A. Viola, Susan Chater
Purpose: To the assessment of common symptoms and concerns of patients who are approaching the ends of their lives
Population: Terminal patients
Age Range : 43 to 88 years
Type of Instrument: Symptom
Mode of Administration:

Rater:	Interviewer-administered
Time required:	15-60 minutes
Response Options:	Likert scale
Scoring:	Global score Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 13
Original Language: English

Contact for information and permission to use:

Keith G. Wilson, Ph.D
Institute for Rehabilitation Research and Development,
The Rehabilitation Centre,
505 Smyth Road
Ottawa ON K1H 8M2 Canada
Tel: 613-737-7350
E-Mail: kewilson@ottawahospital.on.ca

Dimensions covered by the questionnaire :

- Pain and symptoms assessment (5 items)
- End of life concerns (8 items)

Key References:

1. Wilson KG, Scott JF, Graham ID, Kozak JF, Chater S, Viola RA, de Faye BJ, Weaver LA, Curran D. Attitudes of terminally ill patients toward euthanasia and physician-assisted suicide. Arch Intern Med 2000; 160:2454-60.

Background: In jurisdictions that permit euthanasia or physician-assisted suicide, patients with cancer comprise the largest group to die by these methods. We investigated the personal attitudes toward these practices of patients receiving palliative care for advanced cancer. Methods: Seventy patients (32 men and 38 women; median survival, 44.5 days) took part in a survey using in-depth semistructured interviews. The interviews were audiotaped for transcription and content analysis of themes. Results: Most participants (73%) believed that euthanasia or physician-assisted suicide should be legalized, citing pain and the individual's right to choose as their major reasons. Participants who were opposed to legalization cited religious and moral objections as their central concerns. Forty (58%) of the 69 participants who completed the entire interview also believed that, if legal, they might personally make a future request for a hastened death, particularly if pain or physical symptoms became intolerable. Eight of these individuals (12%) would have made such a request at the time of the interview. These 8 participants differed from all others on ratings of loss of interest or pleasure in activities, hopelessness, and the desire to die (Ps<.02). They also had a higher prevalence of depressive disorders (P<.05). However, they did not differ on ratings of pain severity. Conclusions: Many patients with advanced cancer favor policies that would allow them access to both euthanasia and physician-assisted suicide if pain and physical symptoms became intolerable. For patients who would actually make requests for a physician-hastened death, however, psychological considerations may be at least as salient as physical symptoms.

2. Wilson KG, Graham ID, Viola RA, Chater S, de Faye BJ, Weaver LA, Lachance JA. Structured interview assessment of symptoms and concerns in palliative care. Can J Psychiatry. 2004 Jun;49(6):350-8.

Objective: Assessment in palliative care requires a multidimensional review of physical symptoms and psychosocial concerns in a format appropriate for patients with advanced illness. In this study, we describe the initial development and validation of a structured interview for assessing common symptoms and concerns faced by terminally ill individuals. Method: We constructed a 13-item Structured Interview for Symptoms and Concerns (SISC) based on a review of end-of-life issues and administered it to 69 patients receiving palliative care for advanced cancer. Along with the interview, each participant completed visual analog scales (VAS) addressing the same constructs. Test-retest and interrater reliability were determined, as was the concordance between interview ratings and VAS scores. Results: Overall, the interview items had excellent interrater reliability (intraclass correlations were > 0.90) and at least moderate temporal stability (test-retest correlations ranged from 0.50 to 0.90). Concurrent validity was evident in the good concordance between interview items and VAS measures (correlations were > 0.70). The SISC was also sensitive to individual differences between subgroups of participants who did or did not meet diagnostic criteria for anxiety or depressive disorders. Conclusions: This study demonstrates that structured interviews provide a reliable and valid approach to assessment in palliative care and may be an appropriate alternative for some research applications.

STRUCTURED INTERVIEW FOR SYMPTOMS AND CONCERNS

Keith G. Wilson, Ph.D.
Ian D. Graham, Ph.D.
Raymond A. Viola, M.D., M.Sc
Susan Chater, M.B.

PAIN AND SYMPTOM ASSESSMENT

Now I would like to ask you about different bodily symptoms and problems that you may or may not be having.

***Interviewer:** When specific ratings are unclear, it may be helpful to have the subject select his or her own most appropriate verbal descriptor.

1. PAIN

Do you have any pain?
(How bad does it get?)
(Does it interfere with activities you would like to do?)
(Is it a problem for you?)
(Does it come and go, or do you feel that way all the time?)
(How much does it bother you?)
(Does medication help?)

0 **No Pain**
1 **Minimal**, e.g. occasional but infrequent experience of pain-related discomfort or background pain at a very low level; does not interfere with activities; not regarded as a particular problem.
2 **Mild**, e.g. sometimes experiences a low level of pain-related discomfort; may on occasion interfere with some activities; generally controlled with medication; occasionally regarded as a minor problem.
3 **Moderate**, e.g. definite periods of pain - related discomfort; interferes with some activities; helped, but not always completely controlled with medication; regarded as a significant problem.
4 **Strong**, e.g. regularly experiences pain-related discomfort, sometimes quite severely; interferes with many activities; helped but not well-controlled with medication; regarded as a prominent and ongoing problem.
5 **Severe**, e.g. pain is almost always present and often severe; interferes with almost all activities; medication provides little relief; regarded as a troubling, serious ongoing problem.
6 **Extreme**, e.g. pain is constant and severe; interferes with all activities; medication provides minimal relief; regarded as a pervasive, consuming and constant problem.

2. DROWSINESS

Do you feel drowsy or sleepy?
(How strong does it get?)
(Does it interfere with activities you would like to do?)
(Is it a problem for you?)
(Does it come and go, or do you feel that way all the time?)
(How much does it bother you?)

0 **No Drowsiness**
1 **Minimal**, e.g. occasional but infrequent episodes of drowsiness or background drowsiness at a very low level; does not interfere with activities; not regarded as a particular problem.
2 **Mild**, e.g. sometimes experiences a low level of drowsiness; may on occasion interfere with some activities; occasionally regarded as a minor problem.
3 **Moderate**, e.g. definite periods of clear drowsiness; interferes with some activities; regarded as a significant problem.
4 **Strong**, e.g. regularly experiences pervasive episodes of drowsiness, sometimes to the point of having difficulty remaining awake; interferes with many activities; regarded as a prominent and ongoing problem.
5 **Severe**, e.g. drowsiness is almost always present, often to the point of having difficulty remaining awake; interferes with almost all activities; regarded as a troubling, serious ongoing problem.
6 **Extreme**, e.g. constantly drowsy and can barely remain alert; interferes with all activities; regarded as a pervasive, consuming and constant problem.

3. NAUSEA

Do you get nauseous, or feeling like you could throw up?
(How bad does it get?)
(Does it interfere with activities you would like to do?)
(Is it a problem for you?)
(Does it come and go, or do you feel that way all the time?)
(How much does it bother you?)

0 **No Nausea.**
1 **Minimal**, e.g. occasional but infrequent episodes of nausea, or background nausea at a very low level; does not interfere with activities; not regarded as a particular problem.
2 **Mild**, e.g. sometimes experiences a low level of nausea; may on occasion interfere with some activities; occasionally regarded as a minor problem.
3 **Moderate**, e.g. definite periods of clear nausea; interferes with some activities; regarded as a significant problem.
4 **Strong**, e.g. regularly experiences strong episodes of nausea; interferes with many activities; regarded as a prominent and ongoing problem.
5 **Severe**, e.g. nausea is almost always present; interferes with almost all activities; regarded as a serious ongoing problem.
6 **Extreme**, e.g. constantly nauseous and almost always feels like vomiting; interferes with all activities; regarded as a pervasive, consuming and constant problem.

4. **WEAKNESS**

Do you feel weak?
(How bad does it get?)
(Does it interfere with activities you would like to do?)
(Is it a problem for you?)
(Does it come and go, or do you feel that way all the time?)
(How much does it bother you?)

0 **No Weakness**
1 **Minimal**, e.g. occasional but infrequent episodes of generalized weakness or background weakness at a very low level; does not interfere with activities; not regarded as a particular problem.
2 **Mild**, e.g. low level of weakness; may on occasion interfere with some activities; occasionally regarded as a minor problem.
3 **Moderate**, e.g. definite periods of clear weakness; interferes with some activities; regarded as a significant problem.
4 **Strong**, e.g. regularly experiences pervasive episodes of weakness, sometimes to the point of being unable to get out of bed; interferes with many activities; regarded as a significant and ongoing problem.
5 **Severe**, e.g. weakness is almost always present, and often to the point of being unable to get out of bed; interferes with almost all activities; regarded as a troubling, serious ongoing problem.
6 **Extreme**, e.g. constantly very weak and unable to get out of bed; interferes with all activities.

5. **BREATHLESSNESS**

Do you feel breathless, or have trouble breathing?
(How bad does it get?)
(Does it interfere with activities you would like to do?)
(Is it a problem for you?)
(Does it come and go, or do you feel that way all the time?)
(How much does it bother you?)

0 **No Breathlessness**
1 **Minimal**, e.g. occasional but infrequent episodes of breathlessness , or background breathlessness at a very low level; does not interfere with activities; not regarded as a particular problem.
2 **Mild**, e.g. sometimes experiences a low level of breathlessness; may on occasion interfere with some activities; occasionally regarded as a minor problem.
3 **Moderate**, e.g. definite periods of clear breathlessness; interferes with some activities; regarded as a significant problem.
4 **Strong**, e.g., regularly experiences pervasive episodes of breathlessness; sometimes to the point of being unable to get out of bed; interferes with many activities; regarded as a prominent and ongoing problem.
5 **Severe**, e.g. breathlessness is almost constant and often to the point of being unable to get out of bed; interferes with almost all activities; regarded as a troubling serious ongoing problem.
6 **Extreme**, e.g. constantly breathless and unable to get out of bed; interferes with all activities; regarded as a pervasive, consuming and constant problem.

END-OF-LIFE CONCERNS

6. SENSE OF CONTROL

With these different problems you have, do you still basically feel that you are coping and that you can handle the situation?
(Even though you are not feeling well, can you still tolerate things?)
(Do you feel like you are managing to cope?)
(Do you tend to get overwhelmed to the point that you feel like you are losing the ability to cope?)
(Is it a problem for you?)
(Does it come and go, or do you feel that way all the time?)
(How much does it bother you?)

0 **No Sense of Loss of Control**
1 **Minimal**, e.g. only occasionally feels some sense of loss of control, but it is not regarded as a particular problem
2 **Mild**, e.g. sometimes experiences low-grade worry about the possibility of not being able to cope; may occasionally (but frequently) feel somewhat overwhelmed; occasionally regarded as a minor problem.
3 **Moderate**, e.g. definite concerns about loss of control or not being able to cope; may often feel overwhelmed; regarded as a significant problem.
4 **Strong**, e.g. most of the time feels on the edge of not being able to cope; often feels overwhelmed; regarded as a prominent and ongoing problem.
5 **Severe**, e.g. sense of not being able to cope is almost always present; frequently feels overwhelmed; regarded as a troubling, serious and ongoing problem.
6 **Extreme**, e.g., sense of not being able to cope is virtually constant; experiences a basic breakdown of the capacity to cope; very frequently overwhelmed; regarded as a pervasive, consuming, and constant problem.

7. SENSE OF DIGNITY

Do you feel that you are able to maintain your dignity and self-respect?
(Even though you may need help with some things, is your sense of dignity basically intact?)
(Do your medical problems make you feel ashamed, degraded, or embarrassed?)
(Do you feel devalued as a person?)
(Is it a problem for you?)
(Does it come and go, or do you feel that way all the time?)
(How much does it bother you?)

0 **No Loss of Dignity**
1 **Minimal**, e.g. only occasionally feels some loss of dignity; not regarded as a particular problem.
2 **Mild**, e.g. sometimes experiences low-grade worry about loss of dignity; may occasionally(but infrequently) feel somewhat ashamed or degraded; occasionally regarded as a minor problem.
3 **Moderate**, e.g. definite concerns about loss of dignity; may often feel somewhat degraded, ashamed, or embarrassed; generally regarded as a significant problem.
4 **Strong**, e.g. most of the time feels a clear sense of loss of dignity; frequently feels degraded, ashamed, or embarrassed; regarded as a prominent and ongoing problem.
5 **Severe**, e.g. sense of loss of dignity is almost always present; very frequently feels degraded, ashamed, or embarrassed; regarded as a troubling, serious, and ongoing problem.
6 **Extreme**, e.g., sense of loss of dignity is virtually constant; almost always feels degraded, ashamed, or embarrassed; regarded as a pervasive, consuming and constant problem.

8. SENSE OF BURDEN

With your current illness, do you feel that you have become a physical or emotional burden for your family?

> ***Interviewer:** If subject does not live with family, substitute closest caregiver or ***"to other people."*** Relate to pre-hospitalization living arrangements.

(Do you think you make things hard for other people?)
(How strongly do you feel that way?)
(Does it come and go or do you feel that way all the time?)
(How much does it bother you?)
(Is it a problem for you?)

0 **No Sense of Burden**
1 **Minimal**, e.g. only occasionally feels like a burden to others, but it is not regarded as a particular concern.
2 **Mild**, e.g. sometimes experiences low-grade sense of being a burden to others, occasionally regarded as a minor worry.
3 **Moderate**, e.g. most of the time has definite concerns about being a burden to others; is quite worried about their welfare; sense of being a burden is regarded as a significant problem.
4 **Strong**, e.g. most of the time has a definite sense of being a heavy burden to others; is very concerned about their welfare; sense of being a burden is regarded as a significant, prominent, and ongoing problem.
5 **Severe**, e.g. sense of being a burden to others is almost always present; deeply worried about the health and welfare of family members; regards sense of being a burden as a troubling, serious, and ongoing problem.
6 **Extreme**, e.g. sense of being a burden to others is virtually constant and always on one's mind; pervasive sense of being a heavy burden; is extremely concerned about being the cause of deterioration in the health or welfare of loved ones; regards sense of being a burden as pervasive, consuming and constant problem.

9. **ANXIETY**

Have you been feeling nervous, tense, or anxious?
(How bad does it get?)
(Does it come and go?)
(Do you feel that way most of the time?)
(Is it a problem for you?)

0 **No Anxiety**
1 **Minimal.** e.g only occasionally has feelings of anxiety at a low level; not regarded as a particular problem.
2 **Mild.** e.g. sometimes feels somewhat nervous or anxious, but not excessively and not most of the time; occasionally regarded as a minor problem.
3 **Moderate.** e.g. definite periods of uncomfortable anxiety; usually feels at least somewhat nervous or anxious; regarded as a significant problem.
4 **Strong.** e.g. most of the time feels uncomfortably anxious; anxiety is regarded as a prominent and ongoing problem.
5 **Severe.** e.g. almost all of the time feels very anxious; regarded as a troubling, serious, and ongoing problem.
6 **Extreme.** e.g. constant, unrelieved feelings of severe anxiety; regarded as a pervasive, consuming and constant problem.

10. **DEPRESSION**

Have you been feeling «down» or depressed?
(How bad does it get?)
(Is it a problem for you?)
(Does it come and go, or do you feel that way all the time?)
(How much does it bother you?)

0 **No Depression**
1 **Minimal.** e.g. only occasionally has feelings of being «down» or depressed at a low level; not regarded as a particular problem.
2 **Mild.** e.g. sometimes experiences periods of being «down» or depressed, but not excessively and not most of the time; occasionally regarded as a minor problem.
3 **Moderate.** e.g. Definite periods of feeling «down» or depressed; usually feels at least somewhat depressed; regarded as a significant problem.
4 **Strong.** e.g. most of the time feels quite depressed; regarded as a prominent and ongoing problem.
5 **Severe.** e.g. almost all of the time feels very depressed; depression is regarded as a troubling, serious and ongoing problem.
6 **Extreme.** e.g. constant unrelieved feelings of severe depression; regarded as a pervasive, consuming and constant problem.

11. **LOSS OF INTEREST OR PLEASURE**

Do you find that you have little interest or pleasure in doing things?
(How bad does it get?)
(Have you lost interest in almost all activities, or only a few?)
(I'm not thinking so much about your ability to do things as about your interest in them.)
(Even activities that don't require much physical effort, like enjoying your family, friends, reading, watching T.V.?)
(Is it a problem for you?)
(Does it come and go, or do you feel that way all the time?)
(How much does it bother you?)

0 **No Loss of Interest or Pleasure.**
1 **Minimal.** e.g. only occasionally experiences loss of interest or pleasure at a low level; not regarded as a particular problem.
2 **Mild.** e.g sometimes experiences a loss of interest or pleasure in some activities but retains interest in others; occasionally regarded as a minor problem.
3 **Moderate.** e.g. definite loss of interest or pleasure in many activities; regarded as a significant problem.
4 **Strong.** e.g. most of the time feels a markedly diminished interest or pleasure in almost all activities; regarded as a prominent and ongoing problem
5 **Severe.** e.g. almost all of the time feels no interest or pleasure in any activities; regarded as a troubling, serious and ongoing problem.
6 **Extreme.** e.g. complete inability to experience any interest or pleasure in any activities, virtually all the time; regarded as a pervasive, consuming and constant problem.

12. **HOPELESSNESS**

Do you get discouraged, to the point of feeling hopeless?
(Does the future, even over the short term, hold no hope for you of any kind?)
(Are you overcome with a sense of despair about your situation?)
(How bad does it get?)
(Is it a problem for you?)
(Does it come and go, or do you feel that way all the time?)
(How much does it bother you?)

0 **No Hopelessness**
1 **Minimal**. e.g. only occasionally experiences discouragement at a low level; not regarded as a particular problem.
2 **Mild**. e.g. sometimes experiences discouragement at a low level, but not excessively and not most of the time; occasionally regarded as a minor problem.
3 **Moderate**. e.g usually feels at least some sense of discouragement, sometimes to the point feeling hopeless; regarded as a significant problem.
4 **Strong**. e.g. most of the time feels quite discouraged and hopeless; regarded as a prominent and ongoing problem.
5 **Severe**. e.g. almost all of the time feels very hopeless; regarded as a troubling, serious, and ongoing problem.
6 **Extreme**. e.g. constant unrelieved feelings of extreme hopelessness; regarded as a pervasive, consuming and constant problem.

13. **DESIRE FOR DEATH**

Do you ever wish that your illness would progress more quickly so that your suffering could be over sooner?
(Do you ever wish for death?)
(How often do you feel this way?)
(Does it come and go?)
(Is it quite constant or are there times when you don't feel that way?)
(Do you pray for death to come soon?)

0 **No Desire for Death**
1 **Minimal**. e.g. only occasionally has fleeting thoughts;
2 **Mild**. e.g. sometimes feels he/she would like an early death, but not always
3 **Moderate**. e.g. has a genuine desire for early death that is reported to be consistent over time, but is not consumed with the prospect.
4 **Strong**. e.g. most of the time feels a pervasive wish for death to come soon.
5 **Severe**. e.g. almost all of the time has a strong desire for death to come; prays for death.
6 **Extreme**, e.g. constant strong desire for death to come soon; thinks of little else; often prays for death.

SUBJECTIVE QUALITY OF LIFE PROFILE

The Subjective Quality of Life Profile (SQLP) is a self administered, predefined checklist that covers a broad range of domains (functional, social, material, spiritual) and assesses an individual's goals including the importance attributed to the goal, tolerance of the distance between reality and the goal, and the ability to cope with this distance. The core questionnaire contains the unavoidable measurement which is the satisfaction, and the items which will be used in most applications. The optional section of the questionnaire contains other measurements (performance or change, importance attached by the patient, expected change, and coping) and other items for particular populations or specific diseases. It produces a profile of quality of life.

Abbreviated Name: SQLP
Author(s): Alice Dazord
Purpose: To assess Quality of Life in various diseases and in therapeutic trials
Population: Adult
Age Range : 18 and over
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-administered
Time required:	15 minutes
Response Options:	4- to 7-point Likert scale
Scoring:	Scores by items
Score Direction:	Higher scores show better QoL

Number of Items: 29 (core) + optional items available
Original Language: French
Existing Translations : English

Copyright: Script-INSERM

Contact for information and permission to use:

Alice Dazord
Script-INSERM
Hôpital St Jean de Dieu
290, Route de Vienne
69008 Lyon, France
Phone: +33 (0)4 37 90 13 57
Fax: +33 (0)4 37 90 13 59

Dimensions covered by the questionnaire :

- Functional life
- Social life
- Material life
- Spiritual life
- Unforeseen domains
- Global assessments

Key References:

1. Gerin P, Dazord A, Boissel J, Chifflet R. Quality of Life Assessment in Therapeutic Trials: Rationale for and Presentation of a more Appropriate Instrument. Fundamental and Clinical Pharmacology 1992; 6:263-276

In therapeutic trials, quality of life studies are usually based on a health model which results in a restrictive view. Therefore, it is important to clearly define the concept of the quality of life, since ambiguous concepts can alter the results. The key to this problem is the clear distinction between the two components of the quality of life, ie subjective and objective. This latter component is the only one considered in the current medical approach. The use of the subjective quality of life introduces a number of methodological problems not found when the objective quality of life is assessed, and thus requires a specific model which can be derived from the model of life goals used by sociologists. This model is presented here and illustrated with some results obtained with a new questionnaire, the Subjective Quality of Life Profile (SQLP) questionnaire. We suggest that both subjective and objective quality of life studies should be considered in order to emphasize the humanistic approach to therapeutic indications.

2. Gerin P, Dazord A, Cialdella P, Leizorovicz A, Boissel JP. [In French] Le questionnaire "Profil de la Qualité de la Vie Subjective " (PQVS) : premiers éléments de la validation. Thérapie 1991;(46):131-138

The questionnaire "Profile of the Subjective Quality of Life" (in french, PQVS) is devoted to the assessment of quality of life in therapeutic trials. On a sample of 588 subjects, factorial analysis confirm that it is not restricted to the assessment of the health, as most of the instruments actually available for that purpose. Its internal consistency is high. Correlations clearly show that its specific questions assessing the degrees of a) satisfaction and b) involvement (concerning each item) are clearly understood as having different meanings. Multiple regressions demonstrate that these specific questions strongly contribute to the explanation of the global quality of life or of the satisfaction concerning each item. Its reliability is good. It is very well accepted, and completed in no more than 15 to 30 minutes. This questionnaire is thus matching the criteria defining an effective assessment of the quality of life.

APRET
SCRIPT-INSERM
290 ROUTE DE VIENNE
69373 LYON CEDEX 08
April 25, 1995

SUBJECTIVE QUALITY OF LIFE PROFILE (SQLP)

(To be filled out by the investigator)
Local code # _____
Script code # _____

(These numbers enable us to compile diverse information about you. However it does not allow us to identify you by name. This questionnaire is confidential and anonymous).

PLEASE INDICATE:
* The year that you were born: 19___
* Your sex (check the correct response): ___ Male ___ Female
* Today's date: ___/___/___
day month year

Please reply to each of the following questions by checking the box of the answer that corresponds best to your way of looking at things. Please remember to answer the questions that are on the back of each page.

Not all questions apply to everyone. If a question does not apply to your situation or does not seem relevant, or if you do not know how to answer, or if you do not want to answer the question: please indicate your response in the following manner:

"N" to mean: This question does not apply to me
"?" to mean: I don't know
"R" to mean: I refuse to answer

1. Concerning your physical abilities (or difficulties) to perform the movements you usually do every day (lifting objects, bending over, dressing yourself, washing, climbing stairs),

   You are:

   ☐ Very dissatisfied
   ☐ Somewhat dissatisfied
   ☐ Somewhat satisfied
   ☐ Very satisfied
   ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

2. Concerning your abilities (or difficulties) to go out or move about outside the house,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

3. Concerning your overall fitness, that is you get tired more or less easily,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

4. Concerning how you feel physically (pain for example),

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

5. Concerning your relationships with other people,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

6. Concerning your sleep,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

7. Concerning your abilities (or difficulties) to think or focus your attention,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

8. Concerning your sexuality,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

9. Concerning people's attitudes toward you,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

10. Concerning your meals, what you can eat, or your food,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

11. Concerning the free time that you have (or do not have),

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

12. Concerning your income or the money that you have available to you,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

13. Concerning the time you spend (or do not spend) with friends,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

14. Concerning the fact that you have (or do not have) a professional activity,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

15. Concerning how you feel about yourself,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

16. Concerning your personal or inner life (for example, reflection, reading, meditation, daydreaming),

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

17. Concerning your physical health,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

18. Concerning the fact that you have (or do not have) relationships with close family or friends,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

19. Concerning the fact that you have (or do not have) personal activities or leisure (for example, movies, concerts, sports, vacations, do-it-yourself, cultural or artistic activities...),

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

20. Concerning the fact that you participate (or do not participate) in group activities (for example, cultural, union, religious...),

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

21. Concerning the fact that you live (or do not live) with someone (for example, as a couple, as a family, as a single person...),

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

22. Concerning the material conditions of your daily life,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

23. Concerning your physical abilities,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

24. Concerning the fact that you feel (or do not feel) free,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

25. Concerning the way you see your future,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

26. Concerning the fact that you have (or do not have) a religious faith,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

27. Concerning what is happening in the world (for example, economic, social, political...),

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

28. Concerning your relationship with alcohol,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

29. Concerning your relationship to drugs,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

30. Concerning your attitude about taking medications,

You are:

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied
- ☐ Indifferent (neither satisfied nor dissatisfied)

In your life you consider this to be:

- ☐ Unimportant
- ☐ Somewhat important
- ☐ Very important
- ☐ Extremely important

You expect in the coming months that this will:

- ☐ Change much for the worse
- ☐ Change somewhat for the worse
- ☐ Not change
- ☐ Change somewhat for the better
- ☐ Change much for the better

Thank you for participation

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SWEDISH HEALTH RELATED QUALITY OF LIFE SURVEY

The Swedish Health related Quality of Life Survey (SWED-QUAL) was developed by Brorsson et al. from the measures used in the US Medical Outcomes Study (MOS). The questionnaire, which is designed to measure health related quality of life, consists of 70 items, of which 63 forms two single-item and 11 multiitem dimension scales of Likert type: physical functioning (7 items), mobility (1 item), satisfaction with physical ability (1 item), role limitations due to physical health (3 items), pain (6 items), emotional well-being: positive affect (i.e. positive feelings; 6 items), emotional wellbeing: negative affect (i.e. negative feelings; 6 items), role limitations due to emotional health (3 items), sleep problems (7 items), satisfaction with family life (relations with parents, siblings, children etc.; 4 items), relation to partner (6 items), sexual functioning (4 items) and general health perception (9 items).

Abbreviated Name: Swed–Qual
Author(s): Bengt Brorsson
Purpose: To assess QoL in populations with chronic diseases and make comparisons to population norm data
Population: Adult
Age Range : 18-84 years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-administered
Time required:	10-15 minutes
Response Options:	4-point Likert scale
Scoring:	Global score: Minimum score: 0 / Maximum score: 100 Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 61
Original Language: Swedish
Existing Translations : English

Contact for information and permission to use:

Bengt Brorsson
Swedish Council on Technology Assessment in Health Care
SBUBox 5650
114 86 Stockholm
Sweden
Phone: +46 8 412 32 00
Fax: +46 8 411 32 60
E-mail: Brorsson@sbu.se

Dimensions covered by the questionnaire :

- Physical functioning (7 items)
- Mobility (1 item)
- Satisfaction with Physical Ability (1 item)
- Role Limitation due to Physical Health (3 items)
- Emotional Health (3 items)
- Emotional Well-Being :
  - Positive effect (6 items)
  - Negative effect (6 items)
  - Sleep problems (6 items)
- General Health Perception :
  - Current health (3 items)
  - Prior health (2 items)
  - Resistance to illness (2 items)
  - Health concern (1 item)
- Family Functioning :
  - Satisfaction with family (4 items)
  - Marital functioning (6 items)
  - Sexual functioning (4 items)

Key References:

1. Brorsson B, Ifver J, Hays D. The Swedish Health Related Quality of Life Survey (SWED–QUAL). Quality of Life Research 1993;2(1):33–45

We present a Swedish Health-Related Quality of Life Survey (SWED-QUAL) that was adapted from measures used in the Medical Outcome Study (MOS). The development of these measures spans more than 20 years and their reliability and validity have been extensively tested. The SWED-QUAL consists of 61 items that form 11 multi-item scales tapping aspects of physical, mental, social and general health. The instrument was mailed in 1991 to a random stratified sample of 2,366 individuals from the Swedish general population aged 18-84 years and to a stratified random sample of 2,349 individuals who had been seriously injured in a traffic accident. The response rates were 61% and 59%, respectively. Telephone follow-up of non-responders indicate that most of those tended to have a better health-related quality of life than responders. The SWED-QUAL satisfied all of the psychometric criteria that were evaluated. Multitrait scaling provided strong support for item discrimination. Cronbach's alpha exceeded 0.78 for all scales. Scores tended to be lower among older than younger people, and among females compared to males. The good response rate indicates that the content of the SWED-QUAL is considered relevant by people at large, that the results from the general population sample could be used for comparisons with other samples and the instrument used for further studies of the effectiveness of a broad spectrum of medical interventions.

Swed-Qual
Version 1.0

Frågor om Din hälsa!

Del 1. Fysisk funktionsförmåga

De följande frågorna handlar om aktiviteter som Du kan tänkas utföra en vanlig dag.

1. Är **Ditt hälsotillstånd** för närvarande så bra att Du klarar av att utföra de nedan uppräknade aktiviteterna? (Sätt ett kryss på varje rad)

		Ja, det klarar jag **utan** svårighet	Ja, det klarar jag **med viss** svårighet	Ja, det klarar jag **med stor** svårighet	Nej, det klarar jag **inte alls**
a.	**Ansträngande aktiviteter,** t ex tyngre kroppsarbete eller ansträngande sporter	❑	❑	❑	❑
b.	**Måttligt ansträngande aktiviteter**, som att gå skogspromenader eller arbeta i trädgården	❑	❑	❑	❑
c.	Bära två fulla matkassar 100 meter	❑	❑	❑	❑
d.	Promenera 100 meter	❑	❑	❑	❑
e.	Gå uppför en trappa	❑	❑	❑	❑
f.	Böja Dig och ta upp något från golvet ...	❑	❑	❑	❑
g.	Klä på Dig	❑	❑	❑	❑

2. Hur tillfreds är Du med Din kroppsliga förmåga att göra allt som Du vill göra?

❑ Mycket nöjd

❑ Ganska nöjd

❑ Något missnöjd

❑ Mycket missnöjd

Del 2. Värk och smärta

3. Har Du besvärats av värk eller smärta den **senaste veckan**?

❑ Inte alls → Fortsätt till Del 3, fråga 6 på nästa sida

❑ Några gånger

❑ Ganska ofta

❑ Mycket ofta

4. Hur svår värk eller smärta har Du haft under den **senaste veckan?**

- ❑ Ingen alls
- ❑ Lätt värk eller smärta
- ❑ Måttlig värk eller smärta
- ❑ Svår värk eller smärta
- ❑ Mycket svår värk eller smärta

5. Har värken eller smärtan den **senaste veckan** påverkat Dig när det gäller de nedan uppräknade sakerna?

		Nej, inte alls	Ja, men obetydligt	Ja, ganska mycket	Ja, väldigt mycket
a.	Din förmåga att gå och röra Dig?	❑	❑	❑	❑
b.	Din sömn?	❑	❑	❑	❑
c.	Ditt normala arbete (såväl arbete utanför hemmet som hemarbete)?	❑	❑	❑	❑
d.	Din sinnesstämning?	❑	❑	❑	❑

Del 3. Dagliga uppgifter

Vi ber Dig nu tänka på de dagliga uppgifter som Du anser vara **viktigast** för Dig personligen (t ex arbete i eller utanför hemmet, att vara förälder).

6. Hur ofta har Dina normala uppgifter störts av problem med den **kroppsliga** hälsan den **senaste veckan**? (Sätt ett kryss på varje rad)

		Ofta/oftast	Ibland	Sällan	Aldrig
a.	Jag har uträttat mindre än jag skulle önskat	❑	❑	❑	❑
b.	Jag har utfört uppgifterna mindre noggrant än vanligt	❑	❑	❑	❑
c.	Jag har haft svårt att utföra vissa uppgifter	❑	❑	❑	❑

7. Hur ofta har Dina normala uppgifter störts av **känslomässiga** problem den **senaste veckan?** (Sätt ett kryss på varje rad)

		Ofta/oftast	Ibland	Sällan	Aldrig
a.	Jag har uträttat mindre än jag skulle önskat	❑	❑	❑	❑
b	Jag har utfört uppgifterna mindre noggrant än vanligt	❑	❑	❑	❑
c.	Jag har haft svårt att utföra vissa uppgifter	❑	❑	❑	❑

Del 4. Dina känslor och Din vitalitet

8. Hur väl stämmer följande påståenden in på hur Du känt Dig **den senaste veckan?** (Sätt ett kryss på varje rad)

		Instämmer helt	Instämmer delvis	Tar delvis avstånd	Tar helt avstånd	Kan ej ta ställning
a.	Min tid har varit fylld av sådant som jag tycker är meningsfullt	❑	❑	❑	❑	❑
b.	Jag har känt mig omtyckt	❑	❑	❑	❑	❑
c.	Jag har känt mig nervös	❑	❑	❑	❑	❑
d.	Jag har känt mig spänd	❑	❑	❑	❑	❑
e.	Jag har känt mig nedstämd	❑	❑	❑	❑	❑
f.	Jag har tyckt att jag har mycket att se fram emot	❑	❑	❑	❑	❑
g.	Jag har känt mig harmonisk	❑	❑	❑	❑	❑
h.	Jag har känt mig känslomässigt stabil ..	❑	❑	❑	❑	❑
i.	Jag har känt mig bedrövad	❑	❑	❑	❑	❑
j.	Jag har känt mig rastlös och otålig	❑	❑	❑	❑	❑
k.	Jag har känt mig sur	❑	❑	❑	❑	❑
l.	Jag har känt mig lätt till sinnes	❑	❑	❑	❑	❑

9. Hur väl stämmer följande påståenden in på hur Du upplever Din grad av vitalitet? (Sätt ett kryss på varje rad)

		Instämmer helt	Instämmer delvis	Tar delvis avstånd	Tar helt avstånd	Kan ej ta ställning
a.	Jag har svårt att förstå och lösa problem, fatta beslut och lära mig nya saker	❑	❑	❑	❑	❑
b.	Jag har svårt att göra saker som kräver koncentration och eftertanke	❑	❑	❑	❑	❑
c.	Jag blir lätt förvirrad och kan börja göra flera saker samtidigt	❑	❑	❑	❑	❑
d.	Jag glömmer ibland bort sådant som nyligen inträffat eller t.ex. var jag lagt saker	❑	❑	❑	❑	❑
e.	Jag har svårigheter att koncentrera mig länge på en viss uppgift	❑	❑	❑	❑	❑
f.	Jag reagerar långsamt på sådant som andra säger eller gör	❑	❑	❑	❑	❑

Del 5. Din sömn

10. Instämmer Du i eller tar Du avstånd från följande påståenden rörande Din sömn under **den senaste veckan**? (Sätt ett kryss på varje rad)

		Instämmer helt	Instämmer delvis	Tar delvis avstånd	Tar helt avstånd	Kan ej ta ställning
a.	Jag har sovit oroligt	❑	❑	❑	❑	❑
b.	Jag har fått så mycket sömn att jag känt mig utvilad när jag vaknat på morgonen	❑	❑	❑	❑	❑
c.	Jag har känt mig slö under dagen	❑	❑	❑	❑	❑
d.	Jag har haft svårigheter att somna	❑	❑	❑	❑	❑
e.	Jag har vaknat och haft svårt att somna igen	❑	❑	❑	❑	❑
f.	Jag har haft svårigheter att hålla mig vaken under dagen	❑	❑	❑	❑	❑

Del 6. Ditt allmänna hälsotillstånd

11. Hur bedömer Du Ditt allmänna hälsotillstånd? Är det...

- ❑ Mycket bra
- ❑ Ganska bra
- ❑ Någorlunda
- ❑ Ganska dåligt
- ❑ Mycket dåligt

12. Instämmer Du i eller tar Du avstånd från följande påståenden rörande Ditt allmänna hälsotillstånd? (Sätt ett kryss på varje rad)

	Instämmer helt	Instämmer delvis	Tar delvis avstånd	Tar helt avstånd	Kan ej ta ställning
a. Jag har lika god hälsa som de flesta andra i min ålder	❑	❑	❑	❑	❑
b. Jag har sedan länge besvärats av dålig hälsa	❑	❑	❑	❑	❑
c. Jag har haft problem med min hälsa på senare tid	❑	❑	❑	❑	❑
d. Jag verkar ha lättare att bli sjuk än andra människor	❑	❑	❑	❑	❑
e. Min kropp verkar ha god motståndskraft mot sjukdom	❑	❑	❑	❑	❑
f. Mitt hälsotillstånd utgör ett stort bekymmer för mig i livet	❑	❑	❑	❑	❑

Del 7. Din relation till närstående

13. Tänk på hur Du har det med Din familj. Hur nöjd är Du med följande?

	Mycket nöjd	Ganska nöjd	Något missnöjd	Mycket missnöjd	Kan inte ta ställning	Ej aktuellt
a. Sammanhållningen och samförståndet?	❑	❑	❑	❑	❑	❑
b. Det stöd och de förståelse som ni ger varandra?		❑	❑	❑	❑	❑
c. Den öppenhet som ni visar varandra?	❑	❑	❑	❑	❑	❑

14. Hur nöjd är Du på det hela taget med Ditt hemliv?

- ❑ Mycket nöjd
- ❑ Ganska nöjd
- ❑ Något missnöjd
- ❑ Mycket missnöjd

15. Har Du en make/maka eller partner?

- ❑ Ja
- ❑ Nej

16. Följande påståenden handlar om relationen till Din make/maka, partner, eller annan närstående. (Sätt ett kryss på varje rad)

		Instämmer helt	Instämmer delvis	Tar delvis avstånd	Tar helt avstånd	Kan inte ta ställning	Ej aktuellt
a.	Vi kan tala med varandra om allt eller nästan allt	❑	❑	❑	❑	❑	❑
b.	Vi har problem med att förstå varandras känslor	❑	❑	❑	❑	❑	❑
c.	Vi har svårt att visa starka känslor inför varandra	❑	❑	❑	❑	❑	❑
d.	Jag känner att vi står varandra nära	❑	❑	❑	❑	❑	❑
e.	Jag kan räkna med att han/hon stöder mig om jag får problem	❑	❑	❑	❑	❑	❑
f.	Vi vänder oss oftare till andra än till varandra när vi behöver hjälp och stöd	❑	❑	❑	❑	❑	❑

17. Instämmer Du i eller tar Du avstånd från följande påståenden? (Sätt ett kryss på varje rad)

		Instämmer helt	Instämmer delvis	Tar delvis avstånd	Tar helt avstånd	Kan inte ta ställning	Ej aktuellt
a.	Jag saknar sexuellt intresse	❑	❑	❑	❑	❑	❑
b.	Jag har svårt att slappna av och njuta av sex	❑	❑	❑	❑	❑	❑
c.	Jag har svårigheter att bli sexuellt upptänd	❑	❑	❑	❑	❑	❑
d.	**MÄN**: Jag har svårighet att få och/eller behålla stånd ...	❑	❑	❑	❑	❑	❑
e.	**KVINNOR**: Jag har svårighet att få orgasm	❑	❑	❑	❑	❑	❑

Del 8. Några uppgifter om Dig

18. Hur gammal är Du?

- ❑ 24 år eller yngre
- ❑ 25 –5 4 år
- ❑ 55 – 64 år
- ❑ 65 – 74 år
- ❑ 75 –84 år
- ❑ 85 år eller äldre

19. Är Du man eller kvinna?

- ❑ Man
- ❑ Kvinna

20. Är Du gift?

- ❑ Ja, bor med maka/make
- ❑ Ja, men bor ej med maka/make
- ❑ Nej, är ej gift men är sammanboende
- ❑ Nej, är ej gift och inte sammanboende

21. Vilken utbildning stämmer bäst in på Dig?

- ❑ Grundskola/folkskola
- ❑ Gymnasium/realskola
- ❑ Högskoleutbildning (t ex sjuksköterska)
- ❑ Akademisk examen (t ex fil kand)
- ❑ Annat (ange vad) _____

Tack för besväret!

Swed-Qual
Version 1.0

Questions about your health!

Part 1. Physical functioning

The following items are activities you might do during a typical day.

1. Is **your health** today good enough that you can do the following activities? (Mark one box on each line)

		Yes, **without** difficulty	Yes, with **some** difficulty	Yes, with **great** difficulty	No, **not at all**
a.	**Strenous activities,** e.g. heavy manual work, strenous sports	❑	❑	❑	❑
b.	**Moderately strenuous activities** like hiking in the woods or working in the garden	❑	❑	❑	❑
c.	Carry two baskets filled with groceries 100 m	❑	❑	❑	❑
d.	Walk 100 m	❑	❑	❑	❑
e.	Walk up one flight of stairs	❑	❑	❑	❑
f.	Kneel and pick up something from the floor	❑	❑	❑	❑
g.	Dress yourself	❑	❑	❑	❑

2. How satisfied are you with your physical ability to do all the things that you want to do?

- ❑ Very satisfied
- ❑ Satisfied
- ❑ Dissatisfied
- ❑ Very dissatisfied

Part 2. Aches and pain

3. Have you been bothered by aches or pain during the **last week**?

- ❑ Not at all → Part 3, question 6 on the following page
- ❑ A few times
- ❑ Fairly often
- ❑ Very often

4. How severe has you ache or pain been during the **last week**?

- ❑ None at all
- ❑ Slight ache or pain
- ❑ Moderately severe ache or pain
- ❑ Severe ache or pain
- ❑ Very severe ache or pain

5. Has the ache or pain interfered with you doing the following things during the **last week**?

		No, not at all	Yes, slightly	Yes, fairly much	Yes, very much
a.	Your ability to walk and move around? ...	❑	❑	❑	❑
b.	Your sleep?	❑	❑	❑	❑
c.	Your normal work (includes both work outside the home and house work)	❑	❑	❑	❑
d.	Your mood?	❑	❑	❑	❑

Part 3. Daily activities

Now, please think about the daily activities that are most important for you personally (e.g. work outside the home, house work, hobbies and other recreational activities).

6. How often has your normal activities been interfered with by **physical** problems during the **last week**? (Mark one box on each line)

		Often	Sometimes	Seldom	Never
a.	I accomplished less than I had expected	❑	❑	❑	❑
b.	I did things with less care than I usually do	❑	❑	❑	❑
c.	I had problems when doing certain activities	❑	❑	❑	❑

7. How often has your normal activities been interfered with by **emotional** problems during the **last week**? (Mark one box on each line)

		Often	Sometimes	Seldom	Never
a.	I accomplished less than I had expected	❑	❑	❑	❑
b.	I did things with less care than I usually do		❑	❑	❑
c.	I had problems when doing certain activities	❑	❑	❑	❑

Part 4. Your feelings and your vitality

8. Do you agree or disagree with the following statements concerning your feelings during the **last week**? (Mark one box on each line)

		Completely agree	Partly agree	Partly disagree	Completely disagree	Don't know
a.	My time has been filled with things meaningful to me	❑	❑	❑	❑	❑
b.	I have felt liked	❑	❑	❑	❑	❑
c.	I have felt nervous		❑	❑	❑	❑
d.	I have felt tense	❑	❑	❑	❑	❑
e.	I have felt down	❑	❑	❑	❑	❑
f.	I have felt I have much to look forward to	❑	❑	❑	❑	❑
g.	I have felt harmony	❑	❑	❑	❑	❑
h.	I have felt emotionally stable	❑	❑	❑	❑	❑
i.	I have felt sad	❑	❑	❑	❑	❑
j.	I have felt impatient and restless	❑	❑	❑	❑	❑
k.	I have felt annoyed	❑	❑	❑	❑	❑
l.	I have felt lighthearted	❑	❑	❑	❑	❑

9. Hur väl stämmer följande påståenden in på hur Du upplever Din grad av vitalitet? (Sätt ett kryss på varje rad)

		Completely agree	Partly agree	Partly disagree	Completely disagree	Don't know
a.	I have had difficulty understanding and solving problems, making decisions and learn new things	❑	❑	❑	❑	❑
b.	I have difficulty doing activities involving concentration and thinking	❑	❑	❑	❑	❑
c.	I easily get confused and start several actions at a time	❑	❑	❑	❑	❑
d.	I sometimes forget things that happened recently, e.g. where I put things	❑	❑	❑	❑	❑
e.	I have difficulty keeping my attention any activity for long	❑	❑	❑	❑	❑
f.	I react slowly to things that were said or done	❑	❑	❑	❑	❑

Part 5. Your sleep

10. Do you agree or disagree with the following statements concerning your sleep during the **last week** (Mark one box on each line)

		Completely agree	Partly agree	Partly disagree	Completely disagree	Don't know
a.	I slept poorly	❑	❑	❑	❑	❑
b.	I got so much sleep that I felt rested in the morning	❑	❑	❑	❑	❑
c.	I felt drowsy during the daytime	❑	❑	❑	❑	❑
d.	I have had trouble falling asleep	❑	❑	❑	❑	❑
e.	I have awoke and had difficulty falling asleep again	❑	❑	❑	❑	❑
f.	I have had difficulty staying awake during the daytime	❑	❑	❑	❑	❑

Part 6. Your general health

11. In general, would you say your health is.....

- ❑ Very good
- ❑ Fairly good
- ❑ Fair
- ❑ Rather bad
- ❑ Very bad

12. Do you agree or disagree with the following statements concerning your general state of health? (Mark one box on each line)

		Completely agree	Partly agree	Partly disagree	Completely disagree	Don't know
a.	My health is as good as most others my age	❑	❑	❑	❑	❑
b.	I have been bothered by poor health for a long time	❑	❑	❑	❑	❑
c.	I have been having problems with my health recently	❑	❑	❑	❑	❑
d.	I seem to get ill more easily than other people	❑	❑	❑	❑	❑
e.	My body seems to resist illness quite well	❑	❑	❑	❑	❑
f.	My health status worries me a lot	❑	❑	❑	❑	❑

Part 7. Your family

13. Think about your family. How satisfied are you with the following aspects?

		Very satisfied	Fairly satisfied	Fairly dissatisfied	Very dissatisfied	Don't know	Not applicable
a.	Cohesion and mutual understanding?	❑	❑	❑	❑	❑	❑
b.	The support and understanding you give each other?	❑	❑	❑	❑	❑	❑
c.	The "openness" you show each other?	❑	❑	❑	❑	❑	❑

14. Overall, how satisfied are you with your home life?

- ❑ Very satisfied
- ❑ Fairly satisfied
- ❑ Fairly dissatisfied
- ❑ Very dissatisfied

15. Are you married/ have you a spouse?

- ❑ Yes
- ❑ No

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16. The following statements concern your relationship with your spouse or partner. (Mark one box on each line)

		Completely agree	Partly agree	Partly disagree	Completely disagree	Don't know	Not applicable
a.	We can talk with each other about almost everything	❑	❑	❑	❑	❑	❑
b.	We have difficulties under-standing each others' emotions	❑	❑	❑	❑	❑	❑
c.	We have difficulties showing each other strong emotions	❑	❑	❑	❑	❑	❑
d.	I feel we are close to each other.....	❑	❑	❑	❑	❑	❑
e.	I can count on his/her support if I run into difficulties.....	❑	❑	❑	❑	❑	❑
f.	We turn to others more often than to each other when we need help and support.....	❑	❑	❑	❑	❑	❑

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17. Do you agree or disagree with the following statements? (Mark one box on each line)

		Completely agree	Partly agree	Partly disagree	Completely disagree	Don't know	Not applicable
a.	I lack sexual interest.....	❑	❑	❑	❑	❑	❑
b.	I have difficulties relaxing and enjoying sex	❑	❑	❑	❑	❑	❑
c.	I have difficulties becoming sexually aroused.....	❑	❑	❑	❑	❑	❑
d.	**MEN**: I have difficulties getting and/or keeping an erection.....	❑	❑	❑	❑	❑	❑
e.	**WOMEN**: I have difficulties having an orgasm.....	❑	❑	❑	❑	❑	❑

Part 8. Background information

18. How old are you?

- ❑ 24 or younger
- ❑ 25 –5 4 years of age
- ❑ 55 – 64 years of age
- ❑ 65 – 74 years of age
- ❑ 75 –84 years of age
- ❑ 85 or older

19. Gender?

- ❑ Male
- ❑ Female

20. Social status?

- ❑ Married
- ❑ Single, living with a partner
- ❑ Single, living alone

21. What is your level of education?

- ❑ Primary school
- ❑ Secondary school
- ❑ College
- ❑ University
- ❑ Other (please, specify) _____

Thank you for your generosity in filling in this form!

SYMPTOM CHECKLIST-90-REVISED®

The Symptom Checklist-90-R (SCL-90-R) instrument from Pearson Assessments helps evaluate a broad range of psychological problems and symptoms of psychopathology. The instrument is also useful in measuring patient progress or treatment outcomes. The SCL-90-R instrument is used by clinical psychologists, psychiatrists, and professionals in mental health, medical, and educational settings as well as for research purposes. It can be useful in: Initial evaluation of patients at intake as an objective method for symptom assessment, measuring patient progress during and after treatment to monitor change, outcomes measurement for treatment programs and providers through aggregated patient information, and clinical trials to help measure the changes in symptoms such as depression and anxiety.

Abbreviated Name: SCL-90-R®
Author(s): Leonard R. Derogatis, PhD
Purpose: Designed to screen for a broad range of psychological problems and symptoms of psychopathology, it is also useful as a progress or outcomes measurement instrument
Population: Adult & Adolescents (from 12)
Age Range : 13 and older
Type of Instrument: Symptom/Functioning
Mode of Administration:

Rater:	Self-administered
Time required:	12-15 minutes
Response Options:	5-point rating scale
Scoring:	Scores by dimension Scores or three general indices: global severity index (GSI), Positive Symptom Distress Index (PSDI) and Positive Symptom Total (PST).
Score Direction:	Lower scores show better QoL

Number of Items: 90
Original Language: English
Existing Translations : Dutch, French, German, Spanish, Turkish

Copyright: SCL-90-R is a registered trademark of Leonard R. Derogatis, PhD.

Contact for information and permission to use:

Pearson Assessments
5601 Green Valley Drive
Bloomington, MN 55437
Phone: 1-800-627-7271
NCS Pearson, Inc.
Email: assessment@ncs.com

Dimensions covered by the questionnaire :

- Symptom Scales:
  - Anxiety
  - Hostility
  - Phobic Anxiety
  - Somatization
  - Obsessive / Compulsive
  - Interpersonal Sensitivity
  - Depression
  - Paranoid Ideation
  - Psychoticism
- Global indices:
  - Global severity index
  - Positive symptom distress index
  - Positive symptom total

Key References:

1. Derogatis LR, Lipman RS, Rickels K, Uhlenhuth EH, Covi L. The Hopkins Symptom Checklist (HSCL): a self-report symptom inventory. Behavioral Science 1974;19:1-15
2. Derogatis LR, Lipman RS, Covi L. SCL-90: an outpatient psychiatric rating scale. preliminary report. Psychopharmacology Bulletin 1973;9:13-28

SCL-90-R®

Symptom Checklist-90-R

Leonard R. Derogatis, PhD

Last Name First MI

ID Number

Age Gender Test Date

DIRECTIONS

1. Print your name, identification number, age, gender, and testing date in the area on this page.
2. Use a lead pencil only and make a dark mark when responding to the items on pages 2 and 3.
3. If you want to change an answer, erase it carefully and then fill in your new choice
4. Do not make any marks outside the circles.

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DO NOT SEND TO NATIONAL COMPUTER SYSTEMS
USE ONLY FOR HAND SCORING

INSTRUCTIONS

Below is a list of problems people sometimes have. Please read each on carefully, and blacken the circle that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY.

Blacken the circle for only one number for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example before beginning, and if you have any questions please ask about them.

	NOT AT ALL	A LITTLE BIT	MODER-ATELY	QUITE A BIT	EXTRE-MELY	EXAMPLE HOW MUCH WERE YOU DISTRESSED BY:
66	⓪	①	②	●	④	Bodyaches

	NOT AT ALL	A LITTLE BIT	MODER-ATELY	QUITE A BIT	EXTRE-MELY	HOW MUCH WERE YOU DISTRESSED BY:
1	⓪	①	②	③	④	Headaches
2	⓪	①	②	③	④	Nervousness or shakiness inside
3	⓪	①	②	③	④	Unpleasant thoughts that won't leave your mind
4	⓪	①	②	③	④	Faintness or dizziness
5	⓪	①	②	③	④	Loss of sexual interest or pleasure
6	⓪	①	②	③	④	Feeling critical of others
7	⓪	①	②	③	④	The idea that someone else can control your thoughts
8	⓪	①	②	③	④	Feeling that others are to blame for most of your
9	⓪	①	②	③	④	Trouble remembering things
10	⓪	①	②	③	④	Worried about sloppiness or carelessness
11	⓪	①	②	③	④	Feeling easily annoyed or irritated
12	⓪	①	②	③	④	Pains in heart or chest
13	⓪	①	②	③	④	Feeling afraid in open spaces or on the streets
14	⓪	①	②	③	④	Feeling low in energy or slowed down
15	⓪	①	②	③	④	Thoughts of ending your life
16	⓪	①	②	③	④	Hearing voices that other people do not hear
17	⓪	①	②	③	④	Trembling
18	⓪	①	②	③	④	Feeling that most people cannot be trusted
19	⓪	①	②	③	④	Poor appetite
20	⓪	①	②	③	④	Crying easily
21	⓪	①	②	③	④	Feeling shy or uneasy with the opposite sex
22	⓪	①	②	③	④	Feelings of being trapped or caught
23	⓪	①	②	③	④	Suddenly scared for no reason
24	⓪	①	②	③	④	Temper outbursts that you cannot control
25	⓪	①	②	③	④	Feeling afraid to go out of your house alone
26	⓪	①	②	③	④	Blaming yourself for things
27	⓪	①	②	③	④	Pains in the lower back
28	⓪	①	②	③	④	Feeling blocked in getting things done
29	⓪	①	②	③	④	Feeling lonely
30	⓪	①	②	③	④	Feeling blue
31	⓪	①	②	③	④	Worrying too much about things
32	⓪	①	②	③	④	Feeling no interest in things
33	⓪	①	②	③	④	Feeling fearful
34	⓪	①	②	③	④	Your feelings being easily hurt
35	⓪	①	②	③	④	Other people being aware of your private thoughts
36	⓪	①	②	③	④	Feeling others don't understand you or are
37	⓪	①	②	③	④	Feeling that people are unfriendly or dislike you
38	⓪	①	②	③	④	Having to do things very slowly to ensure correctness
39	⓪	①	②	③	④	Heart pounding or racing

	NOT AT ALL	A LITTLE BIT	MODER-ATELY	QUITE A BIT	EXTRE-MELY	HOW MUCH WERE YOU DISTRESSED BY:
40	⓪	①	②	③	④	Nausea or upset stomach
41	⓪	①	②	③	④	Feeling inferior to others
42	⓪	①	②	③	④	Soreness of your muscles
43	⓪	①	②	③	④	Feeling that you are watched or talked about by others
44	⓪	①	②	③	④	Trouble falling asleep
45	⓪	①	②	③	④	Having to check and double-check what you do
46	⓪	①	②	③	④	Difficulty making decisions
47	⓪	①	②	③	④	Feeling afraid to travel on buses, subways or trains
48	⓪	①	②	③	④	Trouble getting your breath
49	⓪	①	②	③	④	Hot or cold spells
50	⓪	①	②	③	④	Having to avoid certain things, places, or activities
51	⓪	①	②	③	④	Your mind going blank
52	⓪	①	②	③	④	Numbness or tingling in parts of your body
53	⓪	①	②	③	④	A lump in your throat
54	⓪	①	②	③	④	Felling hopelessness about the future
55	⓪	①	②	③	④	Trouble concentrating
56	⓪	①	②	③	④	Feeling weak in parts of your body
57	⓪	①	②	③	④	Feeling tense or keyed up
58	⓪	①	②	③	④	Heavy feelings in your arms or legs
59	⓪	①	②	③	④	Thoughts of death or dying
60	⓪	①	②	③	④	Overeating
61	⓪	①	②	③	④	Feeling uneasy when people are watching or talking
62	⓪	①	②	③	④	Having thoughts that are not your own
63	⓪	①	②	③	④	Having urges to beat, injure or harm someone
64	⓪	①	②	③	④	Awakening in the early morning
65	⓪	①	②	③	④	Having to repeat the same actions such as touching,
66	⓪	①	②	③	④	Sleep that is restless or disturbed
67	⓪	①	②	③	④	Having urges to break or smash things
68	⓪	①	②	③	④	Having ideas or beliefs that others do not share
69	⓪	①	②	③	④	Feeling very self-conscious with others
70	⓪	①	②	③	④	Feeling uneasy in crowds, such as shopping or at a
71	⓪	①	②	③	④	Feeling everything is an effort
72	⓪	①	②	③	④	Spells of terror or panic
73	⓪	①	②	③	④	Feeling uncomfortable about eating or drinking in public
74	⓪	①	②	③	④	Getting into frequent arguments
75	⓪	①	②	③	④	Feeling nervous when you are left alone
76	⓪	①	②	③	④	Others not giving you proper credit for your
77	⓪	①	②	③	④	Feeling lonely even when you are with people
78	⓪	①	②	③	④	Feeling so restless you couldn't sit still
79	⓪	①	②	③	④	Feeling of worthlessness
80	⓪	①	②	③	④	The feeling that something bad is going to happen to
81	⓪	①	②	③	④	Shouting or throwing things
82	⓪	①	②	③	④	Feeling afraid you will faint in public
83	⓪	①	②	③	④	Feeling that people will take advantage of you if you let
84	⓪	①	②	③	④	Having thoughts about sex that bother you a lot
85	⓪	①	②	③	④	The idea that you should be punished for your sins
86	⓪	①	②	③	④	Thoughts or images of a frightening nature
87	⓪	①	②	③	④	The idea that something serious is wrong with your
88	⓪	①	②	③	④	Never feeling close to another person
89	⓪	①	②	③	④	Feelings of guilt
90	⓪	①	②	③	④	The idea that something is wrong with your mind

TNO AZL CHILDREN'S QUALITY OF LIFE

The TNO-AZL Questionnaires for Children's Health-Related Quality of Life (TACQOL) were constructed to enable a systematic, valid and reliable description of Health-Related Quality of Life (HRQoL) of children with chronic diseases aged 6 till 15 by the children themselves or their parents. HRQoL, as assessed by the TACQOL, is defined as childrens health status, weighted by the emotional response of the children themselves to their health status problems.

The questionnaires are designed primarily for research purposes focusing mainly on data aggregated on the group level, for example in clinical trials, evaluative or descriptive studies.

The TACQOL is a generic instrument, measuring general aspects of HRQoL and thereby enabling comparisons to be made between groups of children with various chronic diseases. As other generic HRQoL instruments the TACQOL as such is not adapted to capture those aspects of HRQoL which are specific for all different types of chronic conditions and diseases. For a detailed and sensitive assessment of HRQoL in groups of children with specific chronic diseases, more specific instruments are necessary.

The TACQOL is a multidimensional instrument, with 7 scales. The domains covered by the TACQOL are based on a review of the literature, discussions with experts (child psychologists, paediatricians) and statistical testing. These scales result in a (group) profile. As HRQoL is seen as a multidimensional construct, no total score is calculated.

Both a Parent Form and Child Form are available. The TACQOL-Parent Form (TACQOL-PF) explicitly asks parents to try and assess their child's feelings with regard to functional problems which their child faces, not their own feelings (“true proxy”). The TACQOL-PF is designed for (parents of) children in the age group aged between 6 and 15. The TACQOL–CF is for children aged 8-15.

Abbreviated Name: TACQOL
Author(s): T. Vogels, G.H.W. Verrips, H.M. Koopman, N.C.M. Theunissen, M. Fekkes, R.P. Kamphuis, Verloove-Vanhorick S.P.
Purpose: To assess health related quality of life in children
Population: Pediatric
Age Range : 8 to 15 years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-/ Interviewer-administered
Time required:	10 minutes
Response Options:	Likert scale
Scoring:	Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 56
Original Language: Dutch
Existing Translations : English, Russian, French

Copyright: TNO-Prevention and Health /LUMC, 1999

Contact for information and permission to use:

C.P.F. Van Kempen
Leiden Center for Child Health and Pediatrics LUMC-TNO
Wassenaarseweg 56
P.O. Box 2215
2301 CE LEIDEN
The Netherlands
Phone + 31 71 518 17 17
Fax + 31 71 518 19 20
E-mail: cpf.vankempen@pg.tno.nl

Dimensions covered by the questionnaire :

- Problems/limitations concerning general physical functioning/complaints (8 items)
- Problems/limitations concerning motor functioning (8 items)
- Problems/limitations concerning independent daily functioning (8 items)
- Problems/limitations concerning cognitive functioning and school performances (8 items)
- Problems/limitations in social contacts, with parents and peers (8 items)
- The occurence of positive moods (8 items)
- The occurence of negative moods (8 items)

Key References:

1. Verrips GH, Vogels AGC, Verloove-Vanhorick SP, Fekkes M, Koopman HM, Kamphuis RP, Theunissen NCM, Wit JM. Health-Related Quality of Life Measure for Children - the TACQOL. Journal of Applied Therapeutics 1998; 1/4: 357-360.

2. Vogels T, Verrips GH, Verloove-Vanhorick SP, Fekkes M, Kamphuis RP, Koopman HM, Theunissen NC, Wit JM. Measuring health-related quality of life in children: the development of the TACQOL parent form. Qual Life Res 1998; 7:457-65.

Health-related quality of life (HRQoL), conceptualized as patients' own evaluations of their health status, is an important criterion in evaluation health and health care and in the treatment of individual patients. Until now, few systematic attempts have been made to develop instruments to assess the HRQoL of children using such a conceptualization. This article describes the conceptualization and results of a study aiming to develop such an instrument for children aged 6-15 years using their parents as a proxy. The feasibility and psychometric performance of the instrument were evaluated in a study of 77 patients of the paediatric out-patient clinic of Leiden University Hospital. For each of the a priori-defined domains, a parent form scale could be constructed with satisfactory reliability and moderate correlations with the other scales. Only some of the parents indicating health status problems also signalled negative reactions to these problems. This is, in our view, a strong argument for the distinction between health status and quality of life (QoL). The correlation coefficients between the parent form and a children's questionnaire were low. Overall, the psychometric performance of the TACQOL parent form looks promising, which suggests that this instrument--with some modifications--can indeed be used to assess group differences in HRQoL in children. The results, however, should be replicated in larger samples, currently under study. The relation between parents' proxy reports on the HRQoL of their children and children's self-reports needs further investigation

3. Theunissen NC, Vogels TG, Koopman HM, Verrips GH, Zwinderman KA, Verloove-Vanhorick SP, Wit JM. The proxy problem: child report versus parent report in health-related quality of life research. Qual Life Res 1998; 7:387-97.

This study evaluates the agreement between child and parent reports on children's health-related quality of life (HRQoL) in a representative sample of 1,105 Dutch children (age 8-11 years old). Both children and their parents completed a 56 item questionnaire (TACQOL). The questionnaire contains seven eight-item scales: physical complaints, motor functioning, autonomy, cognitive functioning, social functioning, positive emotions and negative emotions. The Pearson correlations between the child and parent reports were between 0.44 and 0.61 ($p < 0.001$). The intraclass correlations were between 0.39 and 0.62. On average, the children reported a significantly lower HRQoL than their parents on the physical complaints, motor functioning, autonomy, cognitive functioning and positive emotions scales (paired t-test: $p < 0.05$). Agreement on all of the scales was related to the magnitude of the HRQoL scores and to some background variables (gender, age, temporary illness and visiting a physician). According to multitrait-multimethod analyses, both the child and parent reports proved to be valid.

4. Vogels T, Theunissen NCM, Verrips GHW, Koopman HM, Verloove-Vanhorick SPV, Kamphuis RP. Het meten van Kwaliteit van Leven bij kinderen met chronische aandoeningen. De ontwikkeling van de TACQOL vragenlijsten. TIAZ 1996; jaargang 2 nr 3: 104-111.

TACQOL

vragenlijst

voor kinderen van 8 tot en met 15 jaar

Wil je eerst de vragen hieronder invullen?

Ben je een jongen of een meisje? ❑ jongen ❑ meisje

Wanneer ben je geboren? ..... (dag) ..... (maand) ..... (jaar)

Wat is de datum waarop je deze vragenlijst invult? ..... (dag) ..... (maand) ..... (jaar)

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Nummer: [_ _ _ _ _ _ _ _ _ _ _ _]

Hallo

We willen graag weten hoe het de afgelopen weken met jou ging.

Op de volgende bladzijden staat een aantal vragen.
Bij elke vraag staan een paar antwoorden. Kies daaruit het antwoord dat het beste bij jou past.
Zet dan een kruisje in het hokje bij dat antwoord.

Hieronder staat een voorbeeld (je hoeft deze vraag niet zelf in te vullen).

Had je hoofdpijn? ☒ nooit ❑ soms ❑ vaak

1

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Had je keelpijn? ☒ nooit ❑ soms ❑ vaak

2

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Als je de afgelopen weken **geen enkele keer** hoofdpijn had, zet dan een kruisje in het hokje voor 'nooit'.
Dan kun je meteen naar de volgende vraag, over keelpijn. Zoals het voorbeeld hierboven.

Als je **soms** of **vaak** hoofdpijn had, zet je een kruisje bij een van die antwoorden. Daaronder staat de vraag '**Ik voelde me daarbij**'. Vul in hoe je je voelde als je hoofdpijn had. Zoals in het voorbeeld hieronder. Daarna ga je naar de volgende vraag.

Had je hoofdpijn? ❑ nooit ☒ soms ❑ vaak

1

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ☒ slecht

Pijn en klachten in de afgelopen weken

Denk telkens even na hoe het de afgelopen weken was.....

Had je wel eens oor- of keelpijn? ❑ nooit ❑ soms ❑ vaak

1

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Had je wel eens maag- of buikpijn? ❑ nooit ❑ soms ❑ vaak

2

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Had je wel eens hoofdpijn? ❑ nooit ❑ soms ❑ vaak

3

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Was je wel eens duizelig? ❑ nooit ❑ soms ❑ vaak

4

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Was je wel eens misselijk? ❑ nooit ❑ soms ❑ vaak

5

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Was je vermoeid? ❑ nooit ❑ soms ❑ vaak

6

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Was je slaperig? ❑ nooit ❑ soms ❑ vaak

7

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Was je suf? ❑ nooit ❑ soms ❑ vaak

8

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Had je andere pijn of klachten? ❑ nooit ❑ soms ❑ vaak

9

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Wat voor pijn of klachten waren dat?

Alleen als je de afgelopen weken wel eens pijn of klachten had:
Wat denk je, waardoor kwamen die klachten of pijn?

10

Dingen waar je de afgelopen weken wel eens moeite mee had

Denk telkens even na hoe het de afgelopen weken was. Had je wel eens .....

Moeite met rennen? ❑ nooit ❑ soms ❑ vaak

11

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met lopen? ❑ nooit ❑ soms ❑ vaak

12

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met staan? ❑ nooit ❑ soms ❑ vaak

13

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met de trap af lopen? ❑ nooit ❑ soms ❑ vaak

14

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met spelen? ❑ nooit ❑ soms ❑ vaak

15

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met lang hollen of lopen, met je uithoudingsvermogen? ❑ nooit ❑ soms ❑ vaak

16

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met het bewaren van je evenwicht? ❑ nooit ❑ soms ❑ vaak

17

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite om dingen handig en vlug te doen? ❑ nooit ❑ soms ❑ vaak

18

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Alleen als je de afgelopen weken wel eens dit soort problemen had:

Wat denk je, waardoor kwamen die problemen?

19

Dingen waarmee je de afgelopen weken wel eens moeite had

Denk telkens even na hoe het de afgelopen weken was. Had je wel eens .....

Moeite met zelfstandig naar school gaan? ❑ nooit ❑ soms ❑ vaak

20

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met jezelf wassen? ❑ nooit ❑ soms ❑ vaak

21

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met jezelf aankleden? ❑ nooit ❑ soms ❑ vaak

22

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met zelf naar de wc gaan? ❑ nooit ❑ soms ❑ vaak

23

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met zelf eten en drinken? ❑ nooit ❑ soms ❑ vaak

24

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met zelf sporten of buiten spelen? ❑ nooit ❑ soms ❑ vaak

25

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met zelf hobby's uitvoeren? ❑ nooit ❑ soms ❑ vaak

26

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met fietsen? ❑ nooit ❑ soms ❑ vaak

27

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Alleen als je de afgelopen weken wel eens dit soort klachten had:

Wat denk je, waardoor kwamen die problemen?

28

Dingen waar je de afgelopen weken wel eens moeite mee had

Denk telkens even na hoe het de afgelopen weken was. Had je wel eens.....

Moeite met opletten, concentreren? ❑ nooit ❑ soms ❑ vaak

29

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met begrijpen van schoolwerk? ❑ nooit ❑ soms ❑ vaak

30

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met begrijpen wat anderen zeiden? ❑ nooit ❑ soms ❑ vaak

31

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met rekenen? ❑ nooit ❑ soms ❑ vaak

32

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met lezen? ❑ nooit ❑ soms ❑ vaak

33

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met schrijven? ❑ nooit ❑ soms ❑ vaak

34

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met leren? ❑ nooit ❑ soms ❑ vaak

35

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite om uit je woorden te komen? ❑ nooit ❑ soms ❑ vaak

36

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Alleen als je de afgelopen weken wel eens dit soort problemen had:

Wat denk je, waardoor kwamen die problemen?

37

De omgang met andere kinderen en je ouders, de afgelopen weken

Denk telkens even na hoe je de afgelopen weken was.

Ik kon met andere kinderen prettig spelen of praten. ❑ ja ❑ te weinig ❑ nooit

38

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Ik kon bij andere kinderen voor mezelf opkomen. ❑ ja ❑ te weinig ❑ nooit

39

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Andere kinderen vroegen me om mee te doen met spelen. ❑ ja ❑ te weinig ❑ nooit

40

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Ik was bij andere kinderen op mijn gemak. ❑ ja ❑ te weinig ❑ nooit

41

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Ik kon met mijn ouders prettig spelen of praten. ❑ ja ❑ te weinig ❑ nooit

42

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Tegenover mijn ouders was ik zwijgzaam en stil. ❑ nooit ❑ soms ❑ vaak

43

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Ik was onrustig of ongeduldig tegenover mijn ouders. ❑ nooit ❑ soms ❑ vaak

44

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Ik was opstandig tegenover mijn ouders. ❑ nooit ❑ soms ❑ vaak

45

Ik voelde me daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Alleen als je de afgelopen weken niet altijd goed kon opschieten met andere kinderen of je ouders:
Wat denk je, waardoor kwam dat?

46

Ik voelde me de afgelopen weken .....

Vrolijk 47	❑ nooit	❑ soms	❑ vaak	**Ontspannen** 55	❑ nooit	❑ soms	❑ vaak
Verdrietig 48	❑ nooit	❑ soms	❑ vaak	**Agressief** 56	❑ nooit	❑ soms	❑ vaak
Opgewekt 49	❑ nooit	❑ soms	❑ vaak	**Gelukkig** 57	❑ nooit	❑ soms	❑ vaak
Boos 50	❑ nooit	❑ soms	❑ vaak	**Driftig** 58	❑ nooit	❑ soms	❑ vaak
Tevreden 51	❑ nooit	❑ soms	❑ vaak	**Zeker van mezelf** 59	❑ nooit	❑ soms	❑ vaak
Bezorgd 52	❑ nooit	❑ soms	❑ vaak	**Jaloers** 60	❑ nooit	❑ soms	❑ vaak
Enthousiast 53	❑ nooit	❑ soms	❑ vaak	**Blij** 61	❑ nooit	❑ soms	❑ vaak
Somber 54	❑ nooit	❑ soms	❑ vaak	**Angstig** 62	❑ nooit	❑ soms	❑ vaak

Als je je de afgelopen weken niet altijd prettig voelde:
Wat denk je, waardoor kwam dat?
63

_____

Dit is het einde van de vragenlijst. Hartelijk bedankt voor het invullen!

TACQOL

vragenlijst

voor de ouders / verzorgers van
kinderen van 6 tot en met 15 jaar

Wilt u eerst onderstaande vragen beantwoorden?

Is het kind, waarover u deze lijst invult een jongen of een meisje? ❑ jongen ❑ meisje

Wat is de geboortedatum van het kind? ..... (dag) ..... (maand) ..... (jaar)

Op welke dag is deze vragenlijst ingevuld? ..... (dag) ..... (maand) ..... (jaar)

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Nummer: [_ _ _ _ _ _ _ _]

Geachte ouders, verzorgers

Wij willen graag weten hoe het met uw kind ging, in de afgelopen weken.

Op de volgende bladzijden staat een aantal vragen.
Bij elke vraag staan een paar antwoorden. Kies daaruit het antwoord dat het beste bij uw kind past.
Zet een kruisje in het hokje bij dat antwoord.

Hieronder staat een voorbeeld (u hoeft deze vraag niet zelf in te vullen).

Had uw kind hoofdpijn? ☒ nooit ❑ soms ❑ vaak

1

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Had uw kind keelpijn? ☒ nooit ❑ soms ❑ vaak

2

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Als uw kind de afgelopen weken **geen enkele keer** hoofdpijn had, zet u een kruisje in het hokje voor 'nooit'.
Dan kunt u meteen naar de volgende vraag, over keelpijn. Zoals in het voorbeeld hierboven.

Als uw kind **soms** of **vaak** hoofdpijn had, zet een kruisje in het betreffende hokje. Daaronder staat:
'Mijn kind voelde zich daarbij'. Kruis daar dan aan hoe uw kind zich voelde als het hoofdpijn had. Zoals in het voorbeeld hieronder. Daarna gaat u door naar de volgende vraag.

Had uw kind hoofdpijn? ❑ nooit ☒ soms ❑ vaak

1

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ☒ slecht

Pijn en klachten in de afgelopen weken

Denk telkens even na hoe het de afgelopen weken was

Had uw kind wel eens oor- of keelpijn? ❑ nooit ❑ soms ❑ vaak

1

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Had uw kind wel eens maag- of buikpijn? ❑ nooit ❑ soms ❑ vaak

2

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Had uw kind wel eens hoofdpijn? ❑ nooit ❑ soms ❑ vaak

3

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Was uw kind wel eens duizelig? ❑ nooit ❑ soms ❑ vaak

4

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Was uw kind wel eens misselijk? ❑ nooit ❑ soms ❑ vaak

5

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Was uw kind vermoeid? ❑ nooit ❑ soms ❑ vaak

6

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Was uw kind slaperig? ❑ nooit ❑ soms ❑ vaak

7

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Was uw kind suf? ❑ nooit ❑ soms ❑ vaak

8

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Had uw kind andere pijn of klachten? ❑ nooit ❑ soms ❑ vaak

9

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Wat voor pijn of klachten waren dat?

Alleen als uw kind wel eens pijn of klachten had in de afgelopen weken:
Waardoor kwamen die pijn of klachten, naar uw mening?

10

Dingen waarmee uw kind de afgelopen weken wel eens moeite had

Denk telkens even na hoe het de afgelopen weken was. Had uw kind wel eens .....

Moeite met rennen? ❑ nooit ❑ soms ❑ vaak

11

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met lopen? ❑ nooit ❑ soms ❑ vaak

12

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met staan? ❑ nooit ❑ soms ❑ vaak

13

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met de trap af lopen? ❑ nooit ❑ soms ❑ vaak

14

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met spelen? ❑ nooit ❑ soms ❑ vaak

15

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met lang hollen of lopen, met het uithoudingsvermogen? ❑ nooit ❑ soms ❑ vaak

16

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met het bewaren van het evenwicht? ❑ nooit ❑ soms ❑ vaak

17

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite om dingen handig en vlug te doen? ❑ nooit ❑ soms ❑ vaak

18

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Alleen als uw kind dit soort problemen wel eens had in de afgelopen weken:

Waardoor kwamen die problemen, naar uw mening?

19

Dingen waarmee uw kind de afgelopen weken wel eens moeite had

Denkt u telkens even na hoe het de afgelopen weken was. Had uw kind wel eens .....

Moeite met zelfstandig naar school gaan? ❑ nooit ❑ soms ❑ vaak

20

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met zichzelf wassen? ❑ nooit ❑ soms ❑ vaak

21

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met zichzelf aankleden? ❑ nooit ❑ soms ❑ vaak

22

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met zelf naar de wc gaan? ❑ nooit ❑ soms ❑ vaak

23

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met zelf eten en drinken? ❑ nooit ❑ soms ❑ vaak

24

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met zelf sporten of buiten spelen? ❑ nooit ❑ soms ❑ vaak

25

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met zelf hobby's uitvoeren? ❑ nooit ❑ soms ❑ vaak

26

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met fietsen? ❑ nooit ❑ soms ❑ vaak

27

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Alleen als uw kind dit soort problemen wel eens had in de afgelopen weken:

Waardoor kwamen die problemen, naar uw mening?

28

Dingen waar uw kind de afgelopen weken wel eens moeite mee had

Denkt u telkens even na hoe het de afgelopen weken was. Had uw kind wel eens .....

Moeite met opletten, concentreren? ❑ nooit ❑ soms ❑ vaak

29

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met begrijpen van schoolwerk? ❑ nooit ❑ soms ❑ vaak

30

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met begrijpen wat anderen zeiden? ❑ nooit ❑ soms ❑ vaak

31

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met rekenen? ❑ nooit ❑ soms ❑ vaak

32

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met lezen? ❑ nooit ❑ soms ❑ vaak

33

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met schrijven? ❑ nooit ❑ soms ❑ vaak

34

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met leren? ❑ nooit ❑ soms ❑ vaak

35

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite om uit zijn/haar woorden te komen? ❑ nooit ❑ soms ❑ vaak

36

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Alleen als uw kind dit soort problemen wel eens had in de afgelopen weken:

Waardoor kwamen die problemen, naar uw mening?

37

De omgang met andere kinderen en met u, in de afgelopen weken

Denkt u telkens even na hoe het de afgelopen weken was.

Mijn kind kon met andere kinderen prettig spelen of praten. ❑ ja ❑ te weinig ❑ nooit

38

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Mijn kind kon bij andere kinderen voor zichzelf opkomen. ❑ ja ❑ te weinig ❑ nooit

39

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Andere kinderen vroegen mijn kind om mee te doen met spelen. ❑ ja ❑ te weinig ❑ nooit

40

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Mijn kind was bij andere kinderen op zijn gemak. ❑ ja ❑ te weinig ❑ nooit

41

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Mijn kind kon met ons, ouder(s) prettig spelen of praten. ❑ ja ❑ te weinig ❑ nooit

42

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Tegenover ons, ouder(s) was mijn kind zwijgzaam en stil. ❑ nooit ❑ soms ❑ vaak

43

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Mijn kind was onrustig of ongeduldig tegenover ons, ouder(s). ❑ nooit ❑ soms ❑ vaak

44

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Mijn kind was opstandig tegenover ons, ouder(s). ❑ nooit ❑ soms ❑ vaak

45

Mijn kind voelde zich daarbij:
❑ (heel) goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Alleen als het niet altijd goed ging in de omgang met andere kinderen of met u:
Waardoor kwam dat, naar uw mening?

46

Mijn kind voelde zich de afgelopen weken....

Vrolijk 47	❑ nooit	❑ soms	❑ vaak	**Ontspannen** 55	❑ nooit	❑ soms	❑ vaak
Verdrietig 48	❑ nooit	❑ soms	❑ vaak	**Agressief** 56	❑ nooit	❑ soms	❑ vaak
Opgewekt 49	❑ nooit	❑ soms	❑ vaak	**Gelukkig** 57	❑ nooit	❑ soms	❑ vaak
Boos 50	❑ nooit	❑ soms	❑ vaak	**Driftig** 58	❑ nooit	❑ soms	❑ vaak
Tevreden 51	❑ nooit	❑ soms	❑ vaak	**Zeker van zichzelf** 59	❑ nooit	❑ soms	❑ vaak
Bezorgd 52	❑ nooit	❑ soms	❑ vaak	**Jaloers** 60	❑ nooit	❑ soms	❑ vaak
Enthousiast 53	❑ nooit	❑ soms	❑ vaak	**Blij** 61	❑ nooit	❑ soms	❑ vaak
Somber 54	❑ nooit	❑ soms	❑ vaak	**Angstig** 62	❑ nooit	❑ soms	❑ vaak

Als uw kind zich de afgelopen weken niet altijd prettig voelde:
Waardoor kwam dat dan?
63

Hartelijk dank voor het invullen van deze lijst! Als er nog iets is dat wij vergeten zijn en u vindt dat wel belangrijk, dan kunt u dat hieronder opschrijven.

TACQOL

Questionnaire

for children aged 8 to 15

Would you please answer the following questions first?

Are you a boy or a girl? ❑ boy ❑ girl

What is your date of birth? ..... (month) ..... (day) ..... (year)

On what date did you complete this questionnaire? ..... (month) ..... (day) ..... (year)

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Number: [_ _ _ _ _ _ _ _ _ _ _ _]

Hello

We would like to know how you have been in recent weeks.

On the pages which follow, you will find a number of questions.
For each question there are a number of answers you may choose from.
Choose the answer which is the most appropriate for you and place a cross in the box alongside that answer.

For example (you do not need to answer this question):

Have you had headaches? ☒ never ☐ occasionally ☐ often

1

At that time, I felt:

☐ fine ☐ not so good ☐ quite bad ☐ bad

Have you had earaches or sore throats? ☐ never ☒ occasionally ☐ often

2

At that time, I felt:

☐ fine ☐ not so good ☒ quite bad ☐ bad

If you have **not** suffered from headaches **at all** in recent weeks, place a cross in the box next to 'never'. You can then go on to the next question about sore throats as in the example above.

If you had a headache "occasionally" or "often", place a cross in the appropriate box. Below these boxes, you find the words: '**At that time, I felt:**'. You then cross the box stating how you felt when you had a headache.

For example:

Have you had headaches? ☐ never ☒ occasionally ☐ often

1

At that time, I felt:

☐ fine ☐ not so good ☐ quite bad ☒ bad

You then proceed to the next question.

Pain and symptoms in recent weeks

Try to remember how you were in recent weeks ...

Have you had earaches or sore throats? ❑ never ❑ occasionally ❑ often

1

At that time, I felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Have you had stomach-aches or abdominal pain? ❑ never ❑ occasionally ❑ often

2

At that time, I felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Have you had headaches? ❑ never ❑ occasionally ❑ often

3

At that time, I felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Have you been dizzy? ❑ never ❑ occasionally ❑ often

4

At that time, I felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Have you felt sick/nauseous? ❑ never ❑ occasionally ❑ often

5

At that time, I felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Have you felt tired? ❑ never ❑ occasionally ❑ often

6

At that time, I felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Have you felt sleepy? ❑ never ❑ occasionally ❑ often

7

At that time, I felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Have you felt dozy? ❑ never ❑ occasionally ❑ often

8

At that time, I felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Did you suffer from pain or other symptoms? ❑ never ❑ occasionally ❑ often

9

At that time, I felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

What sort of pains or symptoms?

Only if you suffered from pains or other symptoms in recent weeks:

What do you think caused those pains or those symptoms?

10

Things you had difficulty with in recent weeks

Try to remember how you were in recent weeks. Did you have ...

Difficulty with running? ❑ never ❑ occasionally ❑ often

11

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with walking? ❑ never ❑ occasionally ❑ often

12

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with standing? ❑ never ❑ occasionally ❑ often

13

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty walking downstairs? ❑ never ❑ occasionally ❑ often

14

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with playing? ❑ never ❑ occasionally ❑ often

15

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with running or walking for long periods? ❑ never ❑ occasionally ❑ often

16

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with balance? ❑ never ❑ occasionally ❑ often

17

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with doing things handily or quickly? ❑ never ❑ occasionally ❑ often

18

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Only if you had problems of this kind in recent weeks:

What do you think caused these problems?

19

Things you had difficulty with in recent weeks

Try to remember how you were in recent weeks. Did you have...

Difficulty with going to school on your own? ❑ never ❑ occasionally ❑ often

20

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty washing yourself? ❑ never ❑ occasionally ❑ often

21

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty getting dressed on your own? ❑ never ❑ occasionally ❑ often

22

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty going to the lavatory on your own? ❑ never ❑ occasionally ❑ often

23

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with eating or drinking on your own? ❑ never ❑ occasionally ❑ often

24

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with sports or going out to play on your own? ❑ never ❑ occasionally ❑ often

25

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with doing hobbies on your own? ❑ never ❑ occasionally ❑ often

26

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with riding a bicycle? ❑ never ❑ occasionally ❑ often

27

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Only if you had problems of this kind in recent weeks:

What do you think caused these problems?

28

Things you had difficulty with in recent weeks

Try to remember how you were in recent weeks. Did you have...

Difficulty with paying attention, concentrating? ❑ never ❑ occasionally ❑ often

29

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty understanding schoolwork? ❑ never ❑ occasionally ❑ often

30

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty understanding what others said? ❑ never ❑ occasionally ❑ often

31

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with arithmetic? ❑ never ❑ occasionally ❑ often

32

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with reading? ❑ never ❑ occasionally ❑ often

33

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with writing? ❑ never ❑ occasionally ❑ often

34

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with learning? ❑ never ❑ occasionally ❑ often

35

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty in saying what you meant? ❑ never ❑ occasionally ❑ often

36

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Only if you had problems of this kind in recent weeks:

What do you think caused these problems?

37

Dealings with other children and with your parents in recent weeks

Try to remember how you were in recent weeks.

I was able to play or talk happily with other children. ❑ yes ❑ too little ❑ never

38

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

I was able to stand up for myself with other children. ❑ yes ❑ too little ❑ never

39

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

Other children asked me to play with them. ❑ yes ❑ too little ❑ never

40

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

I felt at ease with other children. ❑ yes ❑ too little ❑ never

41

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

I was able to play or talk happily with my parent(s). ❑ yes ❑ too little ❑ never

42

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

With my parent(s), I was silent, not communicative. ❑ never ❑ occasionally ❑ often

43

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

With my parent(s), I was restless or impatient ❑ never ❑ occasionally ❑ often

44

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

With my parents, I was defiant. ❑ never ❑ occasionally ❑ often

45

At that time, I felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

If things were not always satisfactory in dealings with other children or with your parents:
What do you think was the reason?

46

In recent weeks, I felt...

Joyful 47	❑ never	❑ occasionally	❑ often	**Relaxed** 55	❑ never	❑ occasionally	❑ often
Sad 48	❑ never	❑ occasionally	❑ often	**Aggressive** 56	❑ never	❑ occasionally	❑ often
In good spirits 49	❑ never	❑ occasionally	❑ often	**Happy** 57	❑ never	❑ occasionally	❑ often
Angry 50	❑ never	❑ occasionally	❑ often	**Short-tempered** 58	❑ never	❑ occasionally	❑ often
Contented 51	❑ never	❑ occasionally	❑ often	**Confident** 59	❑ never	❑ occasionally	❑ often
Worried 52	❑ never	❑ occasionally	❑ often	**Jealous** 60	❑ never	❑ occasionally	❑ often
Enthusiastic 53	❑ never	❑ occasionally	❑ often	**Cheerful** 61	❑ never	❑ occasionally	❑ often
Gloomy 54	❑ never	❑ occasionally	❑ often	**Anxious** 62	❑ never	❑ occasionally	❑ often

If you did not always feel fine in recent weeks:
What was the reason?
63

This is the end of the questionnaire
Thank you for completing it !

TACQOL

Questionnaire

for parents / carers of children aged 6 to 15

Would you please answer the following questions first?

Is the child in question a boy or a girl? ❑ boy ❑ girl

What is the child's date of birth? ..... (month) ..... (day) ..... (year)

On what date was this questionnaire completed? ..... (month) ..... (day) ..... (year)

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Number: [_ _ _ _ _ _ _ _ _ _ _ _]

Dear parents,

We wish to know how your child has been in recent weeks.

On the pages which follow, you will find a number of questions.
There are a number of answers for each question.
Choose the answer which is the most appropriate for your child and place a cross in the box alongside that answer.

For example (you do not need to answer this question):

Has your child had headaches?

☒ never ☐ occasionally ☐ often

1

At that time, my child felt:

☐ fine ☐ not so good ☐ quite bad ☐ bad

Has your child had earaches or sore throats?

☐ never ☒ occasionally ☐ often

2

At that time, my child felt:

☐ fine ☐ not so good ☒ quite bad ☐ bad

If your child has **not** suffered from headaches **at all** in recent weeks, place a cross in the box next to 'never'. You can then go on to the next question about sore throats as in the example above.

If your child had a headache "occasionally" or "often", place a cross in the appropriate box. Below these boxes, you find the words: '**At that time, my child felt:**'. You then cross the box stating how your child felt when he or she had a headache.

For example:

Has your child had headaches?

☐ never ☒ occasionally ☐ often

1

At that time, my child felt:

☐ fine ☐ not so good ☐ quite bad ☒ bad

You then proceed to the next question.

Pain and symptoms in recent weeks

Try to remember how your child was in recent weeks

Has your child had earaches or sore throats? ❑ never ❑ occasionally ❑ often

1

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Has your child had stomach-aches or abdominal pain? ❑ never ❑ occasionally ❑ often

2

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Has your child had headaches? ❑ never ❑ occasionally ❑ often

3

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Has your child been dizzy? ❑ never ❑ occasionally ❑ often

4

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Has your child felt sick/nauseous? ❑ never ❑ occasionally ❑ often

5

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Was your child tired? ❑ never ❑ occasionally ❑ often

6

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Was your child sleepy? ❑ never ❑ occasionally ❑ often

7

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Was your child dozy/lethargic? ❑ never ❑ occasionally ❑ often

8

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Did your child suffer from pain or other symptoms? ❑ never ❑ occasionally ❑ often

9

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

What sort of pains or symptoms?

Only if your child suffered from pains or other symptoms in recent weeks:
What do you think caused those pains or those symptoms?

10

Things which your child had difficulty with in recent weeks

Try to remember how your child was in recent weeks. Did he or she have...

Difficulty with running? ❑ never ❑ occasionally ❑ often

11

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with walking? ❑ never ❑ occasionally ❑ often

12

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with standing? ❑ never ❑ occasionally ❑ often

13

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty walking downstairs? ❑ never ❑ occasionally ❑ often

14

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with playing? ❑ never ❑ occasionally ❑ often

15

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with running or walking for long periods, with stamina? ❑ never ❑ occasionally ❑ often

16

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with balance? ❑ never ❑ occasionally ❑ often

17

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with doing things handily or quickly? ❑ never ❑ occasionally ❑ often

18

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Only if your child had problems of this kind in recent weeks:

What do you think caused these problems?

19

Things which your child had difficulty with in recent weeks

Try to remember how your child was in recent weeks. Did he or she have...

Difficulty with going to school on his/her own? ❑ never ❑ occasionally ❑ often

20

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Difficulty washing himself/herself? ❑ never ❑ occasionally ❑ often

21

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Difficulty getting dressed on his/her own? ❑ never ❑ occasionally ❑ often

22

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Difficulty going to the lavatory on his/her own? ❑ never ❑ occasionally ❑ often

23

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Difficulty with eating or drinking on his/her own? ❑ never ❑ occasionally ❑ often

24

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Difficulty with sports or going out to play on his/her own? ❑ never ❑ occasionally ❑ often

25

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Difficulty with doing hobbies on his/her own? ❑ never ❑ occasionally ❑ often

26

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Difficulty with riding a bicycle? ❑ never ❑ occasionally ❑ often

27

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Only if your child had problems of this kind in recent weeks:

What do you think caused these problems?

28

Things which your child had difficulty with in recent weeks

Try to remember how your child was in recent weeks. Did he or she have...

Difficulty with paying attention, concentrating? ❑ never ❑ occasionally ❑ often

29

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Difficulty understanding schoolwork? ❑ never ❑ occasionally ❑ often

30

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Difficulty understanding what others said? ❑ never ❑ occasionally ❑ often

31

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Difficulty with arithmetic? ❑ never ❑ occasionally ❑ often

32

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Difficulty with reading? ❑ never ❑ occasionally ❑ often

33

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Difficulty with writing? ❑ never ❑ occasionally ❑ often

34

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Difficulty with learning? ❑ never ❑ occasionally ❑ often

35

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Difficulty in saying what he/she meant? ❑ never ❑ occasionally ❑ often

36

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Only if your child had problems of this kind in recent weeks:

What do you think caused these problems?

37

Dealings with other children and with you in recent weeks

Try to remember how your child was in recent weeks

My child was able to play or talk happily with other children. ❑ yes ❑ too little ❑ never

38

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

My child was able to stand up for himself/herself with other children. ❑ yes ❑ too little ❑ never

39

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

Other children asked my child to play with them. ❑ yes ❑ too little ❑ never

40

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

My child was at ease with other children. ❑ yes ❑ too little ❑ never

41

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

My child was able to play or talk happily with us - the parent(s). ❑ yes ❑ too little ❑ never

42

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

My child was incommunicative or quiet with us - the parent(s) ❑ never ❑ occasionally ❑ often

43

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

My child was restless or impatient with us - the parent(s) ❑ never ❑ occasionally ❑ often

44

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

My child was defiant with us - the parent(s) ❑ never ❑ occasionally ❑ often

45

At that time, my child felt: ❑ fine ❑ not so good ❑ quite bad ❑ bad

---

If things were not always satisfactory in dealings with other children or with you:
What do you think was the reason?

46

In recent weeks, my child felt...

Joyful 47	❑ never	❑ occasionally	❑ often	**Relaxed** 55	❑ never	❑ occasionally	❑ often
Sad 48	❑ never	❑ occasionally	❑ often	**Aggressive** 56	❑ never	❑ occasionally	❑ often
In good spirits 49	❑ never	❑ occasionally	❑ often	**Happy** 57	❑ never	❑ occasionally	❑ often
Angry 50	❑ never	❑ occasionally	❑ often	**Short-tempered** 58	❑ never	❑ occasionally	❑ often
Contented 51	❑ never	❑ occasionally	❑ often	**Confident** 59	❑ never	❑ occasionally	❑ often
Worried 52	❑ never	❑ occasionally	❑ often	**Jealous** 60	❑ never	❑ occasionally	❑ often
Enthusiastic 53	❑ never	❑ occasionally	❑ often	**Cheerful** 61	❑ never	❑ occasionally	❑ often
Gloomy 54	❑ never	❑ occasionally	❑ often	**Anxious** 62	❑ never	❑ occasionally	❑ often

If your child did not always feel fine in recent weeks:
What was the reason?
63

This is the end of the questionnaire
Thank you for completing it !

TNO-AZL PRESCHOOL CHILDREN QUALITY OF LIFE QUESTIONNAIRE

The TNO-AZL Preschool Children Quality of Life Questionnaire (TAPQOL) is a 43 item questionnaire consisting of 12 multi-item scales that cover the domains physical, social, cognitive, and emotional functioning. The number of items per scale ranges from three to seven. TAPQOL items generally relate to the past three months, but it may be adjusted for specific research's aimed timing. For all scales, the presence of a specific complaint or limitation was scored on a three point scale, namely "never", "occasionally", and "often". The scales "social functioning", "motor functioning", and "communication" are only relevant for children aged 1 years and older

Abbreviated Name: TAPQOL
Author(s): Minne Fekkes, NCM Theunissen, E Brugman, EGH Verrips, HM Koopman, T Vogels
Purpose: To measure parent's perceptions of HRQL in preschool children and to evaluate the impact of diseases and treatments on the different domains of young children's lives.
Population: Children (aged 6 months – 5 years)
Age Range : 1 to 5 years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Proxy-administered
Time required:	10 minutes
Response Options:	Likert scale
Scoring:	Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 43
Original Language: Dutch
Existing Translations : English, French

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Contact for information and permission to use:

CPF van Kempen
Leiden Center for Child Health and Pediatrics
TNO Prevention and Health
Wassenaarseweg 56
PO Box 2215
2301 CE Leiden, The Netherlands
Phone: (+31) 71 518 1717
Fax: (+31) 71 518 1920
Email: cpf.vankempen@pg.tno.nl

Dimensions covered by the questionnaire :

- Physical functioning: includes symptoms (lung problems, stomach problems, skin problems, 9 items), sleeping (4 items), appetite (3 items) and motor functioning (4 items)
- Social functioning: includes problem behaviour (7 items) and social functioning (3 items)
- Cognitive functioning: includes communication (4 items)
- Emotional functioning: includes anxiety (3 items), positive mood (3 items) and liveliness (3 items)

Key References:

1. Fekkes M, Theunissen NCM, Brugman E et al. Development and psychometric evaluation of the TAPQOL: A health-related quality of life instrument for 1-5-year-old children. Quality of Life Research, 2000; 9: 961-972.

The 43-item TNO-AZL Preschool Children Quality of Life (TAPQOL) questionnaire was developed to meet the need for a reliable and valid instrument for measuring parent's perceptions of health-related quality of life (HRQoL) in preschool children. HRQoL was defined as health status in 12 domains weighted by the impact of the health status problems on well-being. The aim of this study was to evaluate the psychometric performance of the TAPQOL. A sample of 121 parents of preterm children completed the TAPQOL questionnaire (response rate 88%) as well as 362 parents of children from the general population (response rate 60%). On the base of Cronbach's alpha, item-rest correlation, and principal component analysis, the TAPQOL scales were constructed from the data for the preterm children sample. The psychometric performance of these scales was evaluated for both the preterm children sample and the general population sample. Cronbach's alpha ranged from 0.66 to 0.88 for the preterm children sample and from 0.43 to 0.84 for the general population sample. The unidimensionality of the separate scales was confirmed by principal component analysis for both the preterm children sample and the general population sample. Spearman's correlation coefficients between scales were, on average, low. T-tests showed that the very preterm children, the children with chronic diseases, the less healthy and the less happy children had lower mean scores on the TAPQOL scales than healthy children, indicating a worse quality of life. This study shows that the TAPQOL is a reliable and valid parent's perception of HRQoL in preschool children. More research is needed to evaluate the psychometric performance of the TAPQOL in different clinical populations.

TAPQOL

Vragenlijst

voor ouders van 1 t/m 5-jarige kinderen

Wilt u eerst onderstaande vragen beantwoorden?

Is het kind, waarover u deze lijst invult, een jongen of een meisje? ❑ jongen ❑ meisje

Wat is de geboortedatum van het kind? ..... (dag) ..... (maand) ..... (jaar)

Wat is de datum waarop u deze vragenlijst invult? ..... (dag) ..... (maand) ..... (jaar)

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Nummer: [_ _ _ _ _ _ _ _]

INSTRUCTIE

Geachte mevrouw/mijnheer,

De vragen in deze lijst gaan over allerlei dingen die te maken hebben met de gezondheid van uw kind. U kunt de vragen beantwoorden door het antwoord aan te kruisen dat het beste bij uw kind past.

Bijvoorbeeld zo:

Had uw kind de afgelopen 3 maanden oorpijn?

Oorpijn	☒ nooit	❑ soms	❑ vaak	
1		**Mijn kind voelde zich daarbij:**		

Als uw kind nooit oorpijn had, zoals in het voorbeeld hierboven, kunt u door naar de volgende vraag.

Als uw kind 'soms' of 'vaak' oorpijn had, zet u een kruisje bij één van die antwoorden. Precies onder deze twee antwoorden vindt u de zin "Mijn kind voelde zich daarbij". Daar geeft u vervolgens aan hoe uw kind zich daarbij voelde. Dus zo:

Had uw kind de afgelopen 3 maanden oorpijn?

Oorpijn	❑ nooit	☒ soms	❑ vaak	
1		**Mijn kind voelde zich daarbij:**		
		❑ goed	❑ niet zo goed	☒ vrij slecht ❑ slecht

Daarna gaat u door naar de volgende vraag.

Dit was een voorbeeld.
Op de volgende bladzijde begint de vragenlijst.

Had uw kind in de afgelopen 3 maanden:

Maag- of buikpijn ❑ nooit ❑ soms ❑ vaak

1

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Krampjes ❑ nooit ❑ soms ❑ vaak

2

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Eczeem ❑ nooit ❑ soms ❑ vaak

3

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Jeuk ❑ nooit ❑ soms ❑ vaak

4

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Droge huid ❑ nooit ❑ soms ❑ vaak

5

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Bronchitis ❑ nooit ❑ soms ❑ vaak

6

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met de ademhaling of longproblemen ❑ nooit ❑ soms ❑ vaak

7

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Was uw kind in de afgelopen 3 maanden:

Benauwd ❑ nooit ❑ soms ❑ vaak

8

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Misselijk ❑ nooit ❑ soms ❑ vaak

9

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Hoe sliep uw kind in de afgelopen 3 maanden?

Sliep uw kind onrustig? ❑ nooit ❑ soms ❑ vaak

10

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Lag uw kind 's nachts wakker? ❑ nooit ❑ soms ❑ vaak

11

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Huilde uw kind 's nachts? ❑ nooit ❑ soms ❑ vaak

12

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Had uw kind moeite om de hele nacht door te slapen? ❑ nooit ❑ soms ❑ vaak

13

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Hoe at en dronk uw kind in de afgelopen 3 maanden?

Had uw kind een slechte eetlust? ❑ nooit ❑ soms ❑ vaak

14

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Had uw kind moeite om voldoende te eten? ❑ nooit ❑ soms ❑ vaak

15

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Weigerde uw kind te eten? ❑ nooit ❑ soms ❑ vaak

16

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Gedrag van uw kind in de afgelopen 3 maanden:

Mijn kind was driftig 17	❑ nooit	❑ soms	❑ vaak
Mijn kind was agressief 18	❑ nooit	❑ soms	❑ vaak
Mijn kind was geprikkeld, geïrriteerd 19	❑ nooit	❑ soms	❑ vaak
Mijn kind was boos 20	❑ nooit	❑ soms	❑ vaak
Mijn kind was onrustig of ongeduldig tegen mij 21	❑ nooit	❑ soms	❑ vaak
Mijn kind was opstandig/dwars tegen mij 22	❑ nooit	❑ soms	❑ vaak
Mijn kind was voor mij onhandelbaar 23	❑ nooit	❑ soms	❑ vaak

Hoe was uw kind in de afgelopen 3 maanden?

Opgewekt 24	❑ nooit	❑ soms	❑ vaak
Blij 25	❑ nooit	❑ soms	❑ vaak
Gelukkig 26	❑ nooit	❑ soms	❑ vaak
Bang 27	❑ nooit	❑ soms	❑ vaak
Gespannen 28	❑ nooit	❑ soms	❑ vaak
Angstig 29	❑ nooit	❑ soms	❑ vaak
Energiek 30	❑ nooit	❑ soms	❑ vaak
Actief 31	❑ nooit	❑ soms	❑ vaak
Levendig 32	❑ nooit	❑ soms	❑ vaak

Is uw kind *jonger* dan 1 jaar en 6 maanden, dan hoeft u de rest van deze vragenlijst **niet** in te vullen.
Hartelijk bedankt voor uw medewerking!

Is uw kind *ouder* dan 1 jaar en 6 maanden,
dan kunt u gewoon doorgaan met het invullen van de vragen op de volgende bladzijden.

Gedrag van uw kind in de afgelopen 3 maanden, met andere kinderen:

Mijn kind kon met andere kinderen prettig spelen ❑ nooit ❑ soms ❑ vaak
33

Mijn kind was bij andere kinderen op zijn/haar gemak ❑ nooit ❑ soms ❑ vaak
34

Mijn kind was zeker van zichzelf bij andere kinderen ❑ nooit ❑ soms ❑ vaak
35

Had uw kind in de afgelopen 3 maanden <u>in vergelijking met leeftijdgenootjes</u>

Moeite met lopen? ❑ nee ❑ ja, een beetje ❑ ja, veel ❑ loopt (nog) niet
36
Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met rennen/hollen ❑ nee ❑ ja, een beetje ❑ ja, veel ❑ rent (nog) niet
37
Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite om zonder hulp de trap op te lopen? ❑ nee ❑ ja, een beetje ❑ ja, veel ❑ loopt (nog) niet
38
Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite met het bewaren van het evenwicht ❑ nee ❑ ja, een beetje ❑ ja, veel
39
Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Had uw kind in de afgelopen 3 maanden <u>in vergelijking met leeftijdgenootjes:</u>

Moeite om te begrijpen wat anderen zeiden? ❑ nooit ❑ soms ❑ vaak

40

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite om duidelijk te praten? ❑ nooit ❑ soms ❑ vaak

41

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite om uit zijn/haar woorden te komen? ❑ nooit ❑ soms ❑ vaak

42

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Moeite om duidelijk te maken wat het wil? ❑ nooit ❑ soms ❑ vaak

43

Mijn kind voelde zich daarbij:
❑ goed ❑ niet zo goed ❑ vrij slecht ❑ slecht

Dit is het einde van de vragenlijst. Hartelijk dank voor het invullen!

TAPQOL

Questionnaire

for parents of children aged 1 to 5

Would you please answer the following questions first?

Is the child in question a boy or a girl?	❑ boy	❑ girl	
What is the child's date of birth?	..... (month)	..... (day)	..... (year)
On what date was this questionnaire completed?	..... (month)	..... (day)	..... (year)

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Number: [_ _ _ _ _ _ _ _]

INSTRUCTIONS

Dear Sir / Madam,

The questions in this questionnaire relate to all kinds of different aspects of your child's health.
You can answer the questions by ticking the answer which best describes your child.

For example:

In the last three months, has your child had ..

Ear-ache ☒ never ☐ occasionally ☐ often

1

At that time, my child felt:

☐ fine ☐ not so good ☐ quite bad ☐ bad

If things were not entirely satisfactory, you are also asked how your child felt when there was a problem.
So, if you say that your child had ear-ache 'occasionally' or 'often', you can state, in the second part of the question, how your child felt at that time,

For example:

In the last three months, has your child had ..

Ear-ache ☐ never ☒ occasionally ☐ often

1

At that time, my child felt:

☐ fine ☐ not so good ☒ quite bad ☐ bad

In the last three months, has your child had ..

Stomach-ache or abdominal pain ❑ never ❑ occasionally ❑ often

1

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Colic ❑ never ❑ occasionally ❑ often

2

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Eczema ❑ never ❑ occasionally ❑ often

3

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Itchiness ❑ never ❑ occasionally ❑ often

4

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Dry skin ❑ never ❑ occasionally ❑ often

5

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Bronchitis ❑ never ❑ occasionally ❑ often

6

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with breathing or lung problems ❑ never ❑ occasionally ❑ often

7

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

In the last three months, has your child been ...

Short of breath ❑ never ❑ occasionally ❑ often
8
At that time, my child felt:
❑ fine ❑ not so good ❑ quite bad ❑ bad

Nauseous ❑ never ❑ occasionally ❑ often
9
At that time, my child felt:
❑ fine ❑ not so good ❑ quite bad ❑ bad

How did your child sleep in the last three months?

Did your child sleep restlessly? ❑ never ❑ occasionally ❑ often
10
At that time, my child felt:
❑ fine ❑ not so good ❑ quite bad ❑ bad

Was your child awake at night? ❑ never ❑ occasionally ❑ often
11
At that time, my child felt:
❑ fine ❑ not so good ❑ quite bad ❑ bad

Did your child cry at night? ❑ never ❑ occasionally ❑ often
12
At that time, my child felt:
❑ fine ❑ not so good ❑ quite bad ❑ bad

Did your child have difficulty sleeping through the night? ❑ never ❑ occasionally ❑ often
13
At that time, my child felt:
❑ fine ❑ not so good ❑ quite bad ❑ bad

How did your child eat and drink in the last three months?

Was your child's appetite poor? ❑ never ❑ occasionally ❑ often

14

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Did your child have difficulty eating enough? ❑ never ❑ occasionally ❑ often

15

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Did your child refuse to eat? ❑ never ❑ occasionally ❑ often

16

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Your child's behaviour in the last three months

My child was short-tempered 17	❑ never	❑ occasionally	❑ often
My child was aggressive 18	❑ never	❑ occasionally	❑ often
My child was irritable 19	❑ never	❑ occasionally	❑ often
My child was angry 20	❑ never	❑ occasionally	❑ often
My child was restless or impatient with me 21	❑ never	❑ occasionally	❑ often
My child was defiant / awkward with me 22	❑ never	❑ occasionally	❑ often
I could not manage my child 23	❑ never	❑ occasionally	❑ often

How was your child in the last three months?

In good spirits 24	❑ never	❑ occasionally	❑ often
Cheerful 25	❑ never	❑ occasionally	❑ often
Happy 26	❑ never	❑ occasionally	❑ often
Frightened 27	❑ never	❑ occasionally	❑ often
Tense 28	❑ never	❑ occasionally	❑ often
Anxious 29	❑ never	❑ occasionally	❑ often
Energetic 30	❑ never	❑ occasionally	❑ often
Active 31	❑ never	❑ occasionally	❑ often
Lively 32	❑ never	❑ occasionally	❑ often

If your child is aged below eighteen months, you do not have to complete the rest of this questionnaire.

If your child is older than eighteen months, you should continue with the questions on the following pages.

How was your child's behaviour with other children in the last three months?

My child was able to play happily with other children
33
❑ never ❑ occasionally ❑ often

My child was at ease with other children
34
❑ never ❑ occasionally ❑ often

My child was confident with other children
35
❑ never ❑ occasionally ❑ often

In the last three months, did your child have, <u>compared to other children of the same age ...</u>

Difficulty with walking
36
❑ no ❑ yes, a little ❑ yes, a lot ❑ cannot walk

At that time, my child felt:
❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with running
37
❑ no ❑ yes, a little ❑ yes, a lot ❑ cannot walk

At that time, my child felt:
❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with walking up stairs without help?
38
❑ no ❑ yes, a little ❑ yes, a lot ❑ cannot walk

At that time, my child felt:
❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty with balance
39
❑ no ❑ yes, a little ❑ yes, a lot ❑ cannot walk

At that time, my child felt:
❑ fine ❑ not so good ❑ quite bad ❑ bad

In the last three months, did your child have, <u>compared to other children of the same age ...</u>

Difficulty in understanding what others said? ❑ never ❑ occasionally ❑ often

40

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty in talking clearly? ❑ never ❑ occasionally ❑ often

41

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty in saying what he / she meant? ❑ never ❑ occasionally ❑ often

42

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

Difficulty in making it clear what he / she wanted? ❑ never ❑ occasionally ❑ often

43

At that time, my child felt:

❑ fine ❑ not so good ❑ quite bad ❑ bad

This is the end of the questionnaire.

Thank you for completing it!

TNO-AZL QUESTIONNAIRE FOR ADULT'S HEALTH-RELATED QUALITY OF LIFE

The TNO-AZL Questionnaire for Adult's Health-related Quality of Life (TAAQOL) consists of 45 questions divided into twelve scales (most of them consist of four items each): gross motor functioning, fine motor functioning, cognition, sleep, pain, social contacts, daily activities, sex, vitality, happiness, depressive mood, and anger. The TAAQOL questionnaire measures just like the TACQOL the emotional impact of self-reported functional problems and has no parent form.

Abbreviated Name: TAAQOL
Author(s): Jeanet Bruil, Minne Fekkes, Ton Vogels, Erik Verrips.
Purpose: To measure a person's health status, weighted by the impact of health status problems on well-being.
Population: Adults (over 16)
Age Range : 16+ years
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-administered
Time required:	10 minutes
Response Options:	Likert scale
Scoring:	Scores by dimension
Score Direction:	Higher scores show better QoL

Number of Items: 45
Original Language: Dutch
Existing Translations : English

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Contact for information and permission to use:

CPF van Kempen
Leiden Center for Child Health and Pediatrics
TNO Prevention and Health
Wassenaarseweg 56
PO Box 2215
2301 CE Leiden, The Netherlands
Phone: (+31) 71 518 1717
Fax: (+31) 71 518 1920
Email: cpf.vankempen@pg.tno.nl

Dimensions covered by the questionnaire :

The TAAQOL includes 12 scales (Cognition, Social contact, Functional status etc).

Key References:

1. Kamphuis M, Ottenkamp J, Vliegen HW, Vogels T, Zwinderman KH, Kamphuis RP, Verloove-Vanhorick SP. Health-related quality of life and health status in adult survivors with previously operated complex congenital heart disease. Heart, 2002, 87(4):356-362

Objective: To examine the impact of previously operated complex congenital heart disease on health related quality of life and subjective health status and to determine the relation between these parameters and physical status. Design: Cross sectional; information on medical follow up was sought retrospectively. Setting: Patients were randomly selected from the archives of the paediatric cardiology department, Leiden University Medical Centre, Leiden, The Netherlands, and approached irrespective of current cardiac care or hospital of follow up. Patients: Seventy eight patients with previously operated complex congenital heart disease (now aged 18-32 years) were compared with the general population. Main Outcome Measures: Health related quality of life was determined with a specifically developed questionnaire (Netherlands Organisation for Applied Scientific Research Academic Medical Centre (TNO-AZL) adult quality of life (TAAQOL)) and subjective health status was assessed with the 36 item short form health survey (SF-36). Physical status was determined with the objective physical index, Somerville index, and New York Heart Association functional class. Results: Health related quality of life of the patients was significantly worse than that of the general population in the dimensions gross motor functioning and vitality ($p < 0.01$). Correlations between health related quality of life and physical status were poor. Patients had significantly worse subjective health status than the general population in the dimensions physical functioning, role functioning physical, vitality, and general health perceptions ($p < 0.01$). Correlations between subjective health status and physical indices were weak. Conclusion: Adult survivors with previously operated complex congenital heart disease experienced limitations only in the physical dimensions of health related quality of life and subjective health status. Objectively measured medical variables were only weakly related to health related quality of life. These results indicate that, when evaluating health related quality of life, dedicated questionnaires such as the TAAQOL should be used.

2. Bruil J, Fekkes M, Vogels T et al. The validity and reliability of the TAAQOL: a health-related quality of life instruments comprising health status weighted by the impact of problems on well being. [Abstract] Quality of Life Research 2001;10(3):257

3. Fekkes M, Kamphuis RP, Ottenkamp J, Verrips E, Vogels T, Kamphuis M, Verloove-Vanhorick SP. Health-related quality of life in young adults with minor congenital heart disease. Psychology and Health 2001, 16: 239-250.

TAAQOL

vragenlijst

voor personen van 16 jaar en ouder

Wilt u eerst de vragen hieronder invullen?

Bent u een man of een vrouw?	❑ man	❑ vrouw	
Wat is uw geboortedatum?	.....	.....	.....
	(dag)	(maand)	(jaar)
Wat is de datum waarop u deze vragenlijst invult?	.....	.....	.....
	(dag)	(maand)	(jaar)

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Nummer: [_ _ _ _ _ _ _ _]

INSTRUCTIE

Geachte heer/mevrouw,

De vragen in deze lijst hebben betrekking op allerlei aspecten van uw gezondheid.
U kunt de vragen beantwoorden door het antwoord aan te kruisen dat het beste bij u past.

Bijvoorbeeld zo:

Ondervond u de afgelopen maand belemmering bij:

Trappen oplopen? ☒ niet ❑ een beetje ❑ tamelijk ❑ veel

1

Hoe erg of vervelend vond u dat?
❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg

Indien iets niet helemaal goed ging, wordt u ook gevraagd hoe erg of vervelend u dat vond.
Dus, als u heeft aangegeven dat u "een beetje" belemmerd werd bij het trappen oplopen, kunt u vervolgens in het tweede gedeelte van de vraag aangeven hoe erg u dat vond.
Zo dus:

Ondervond u de afgelopen maand belemmeringen bij:

Trappen oplopen? ❑ niet ☒ een beetje ❑ tamelijk ❑ veel

1

Hoe erg of vervelend vond u dat?
❑ niet erg ❑ een beetje erg ☒ tamelijk erg ❑ heel erg

Ondervond u de afgelopen maand belemmeringen bij:

Trappen oplopen 1	❑ niet	❑ een beetje ❑ tamelijk ❑ veel	**Hoe erg of vervelend vond u dat?** ❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg
Buigen / knielen / bukken 2	❑ niet	❑ een beetje ❑ tamelijk ❑ veel	**Hoe erg of vervelend vond u dat?** ❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg
Een halve kilometer lopen (bv. een paar straten) 3	❑ niet	❑ een beetje ❑ tamelijk ❑ veel	**Hoe erg of vervelend vond u dat?** ❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg
Tillen (bv boodschappen dragen) 4	❑ niet	❑ een beetje ❑ tamelijk ❑ veel	**Hoe erg of vervelend vond u dat?** ❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg

Ondervond u de afgelopen maand belemmering bij:

Papier knippen met een schaar	❑ niet	❑ een beetje	❑ tamelijk	❑ veel	
5		**Hoe erg of vervelend vond u dat?**			
		❑ niet erg	❑ een beetje erg	❑ tamelijk erg	❑ heel erg
Het dichtknopen van een blouse / overhemd	❑ niet	❑ een beetje	❑ tamelijk	❑ veel	
6		**Hoe erg of vervelend vond u dat?**			
		❑ niet erg	❑ een beetje erg	❑ tamelijk erg	❑ heel erg
Het openmaken van een conservenblikje	❑ niet	❑ een beetje	❑ tamelijk	❑ veel	
7		**Hoe erg of vervelend vond u dat?**			
		❑ niet erg	❑ een beetje erg	❑ tamelijk erg	❑ heel erg
De deksel opendraaien van een potje	❑ niet	❑ een beetje	❑ tamelijk	❑ veel	
8		**Hoe erg of vervelend vond u dat?**			
		❑ niet erg	❑ een beetje erg	❑ tamelijk erg	❑ heel erg

Had u de afgelopen maand:

Moeite met aandachtig luisteren 9	❑ niet	❑ een beetje	❑ tamelijk	❑ veel	
		Hoe erg of vervelend vond u dat?			
		❑ niet erg	❑ een beetje erg	❑ tamelijk erg	❑ heel erg
Moeite met het onthouden van dingen 10	❑ niet	❑ een beetje	❑ tamelijk	❑ veel	
		Hoe erg of vervelend vond u dat?			
		❑ niet erg	❑ een beetje erg	❑ tamelijk erg	❑ heel erg
Moeite met geconcentreerd nadenken 11	❑ niet	❑ een beetje	❑ tamelijk	❑ veel	
		Hoe erg of vervelend vond u dat?			
		❑ niet erg	❑ een beetje erg	❑ tamelijk erg	❑ heel erg
Dat u afdwaalde in gedachten 12	❑ niet	❑ een beetje	❑ tamelijk	❑ veel	
		Hoe erg of vervelend vond u dat?			
		❑ niet erg	❑ een beetje erg	❑ tamelijk erg	❑ heel erg

Hoe vaak kwam het de afgelopen maand voor dat u:

Moeilijk in slaap kon komen

13

❑ nooit ❑ soms ❑ vaak ❑ (bijna) altijd

Hoe erg of vervelend vond u dat?

❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg

Onrustig sliep

14

❑ nooit ❑ soms ❑ vaak ❑ (bijna) altijd

Hoe erg of vervelend vond u dat?

❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg

's Nachts veel wakker lag

15

❑ nooit ❑ soms ❑ vaak ❑ (bijna) altijd

Hoe erg of vervelend vond u dat?

❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg

Een goede nachtrust had

16

❑ (bijna) altijd ❑ vaak ❑ soms ❑ nooit

Als u niet altijd een goede nachtrust had, hoe erg of vervelend vond u dat?

❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg

Had u de afgelopen maand:

Rugpijn ❑ nooit ❑ soms ❑ vaak ❑ (bijna) altijd

17

Hoe erg of vervelend vond u dat?
❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg

Pijn / spanning in nek of schouders ❑ nooit ❑ soms ❑ vaak ❑ (bijna) altijd

18

Hoe erg of vervelend vond u dat?
❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg

Pijn in gewrichten / ledematen ❑ nooit ❑ soms ❑ vaak ❑ (bijna) altijd

19

Hoe erg of vervelend vond u dat?
❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg

Pijn in spieren ❑ nooit ❑ soms ❑ vaak ❑ (bijna) altijd

20

Hoe erg of vervelend vond u dat?
❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg

Indien u daar <u>behoefte</u> aan had, was het voor u de afgelopen maand <u>mogelijk</u> om:

Vertrouwelijk met anderen te praten

21

❑ vaak ❑ soms ❑ zelden ❑ nooit

Als dat niet altijd mogelijk was, hoe erg of vervelend vond u dat?

❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg

Met andere mensen plezier te hebben

22

❑ vaak ❑ soms ❑ zelden ❑ nooit

Als dat niet altijd mogelijk was, hoe erg of vervelend vond u dat?

❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg

Vrienden te bezoeken

23

❑ vaak ❑ soms ❑ zelden ❑ nooit

Als dat niet altijd mogelijk was, hoe erg of vervelend vond u dat?

❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg

Een goed gesprek met anderen te hebben

24

❑ vaak ❑ soms ❑ zelden ❑ nooit

Als dat niet altijd mogelijk was, hoe erg of vervelend vond u dat?

❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg

Had u de afgelopen maand:

Moeite gehad met werk, studie of andere dagelijkse activiteiten 25	❑ niet	❑ een beetje ❑ tamelijk ❑ veel **Hoe erg of vervelend vond u dat?** ❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg	
Minder dan voorheen aan werk, studie of andere dagelijkse activiteiten gedaan 26	❑ niet	❑ een beetje ❑ tamelijk ❑ veel **Hoe erg of vervelend vond u dat?** ❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg	
Belemmeringen gehad om bepaald soort werk, studie of andere dagelijkse activiteiten te doen 27	❑ niet	❑ een beetje ❑ tamelijk ❑ veel **Hoe erg of vervelend vond u dat?** ❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg	
Werk, studie of andere dagelijkse activiteiten minder zorgvuldig gedaan 28	❑ niet	❑ een beetje ❑ tamelijk ❑ veel **Hoe erg of vervelend vond u dat?** ❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg	
Minder dan voorheen aan seks gedaan 29	❑ nee	❑ een beetje ❑ tamelijk ❑ veel **Hoe erg of vervelend vond u dat?** ❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg	
Minder bevrediging aan seks beleefd 30	❑ nee	❑ een beetje ❑ tamelijk ❑ veel **Hoe erg of vervelend vond u dat?** ❑ niet erg ❑ een beetje erg ❑ tamelijk erg ❑ heel erg	

Voelde u zich de afgelopen maand:

Energiek 31	❑ niet	❑ een beetje	❑ tamelijk	❑ erg
Moe 32	❑ niet	❑ een beetje	❑ tamelijk	❑ erg
Fit 33	❑ niet	❑ een beetje	❑ tamelijk	❑ erg
Snel uitgeput 34	❑ niet	❑ een beetje	❑ tamelijk	❑ erg
Vrolijk 35	❑ niet	❑ een beetje	❑ tamelijk	❑ erg
Verdrietig 36	❑ niet	❑ een beetje	❑ tamelijk	❑ erg
Opgewekt 37	❑ niet	❑ een beetje	❑ tamelijk	❑ erg
Boos 38	❑ niet	❑ een beetje	❑ tamelijk	❑ erg
Bezorgd 39	❑ niet	❑ een beetje	❑ tamelijk	❑ erg
Somber 40	❑ niet	❑ een beetje	❑ tamelijk	❑ erg
Agressief 41	❑ niet	❑ een beetje	❑ tamelijk	❑ erg
Gelukkig 42	❑ niet	❑ een beetje	❑ tamelijk	❑ erg
Driftig 43	❑ niet	❑ een beetje	❑ tamelijk	❑ erg
Blij 44	❑ niet	❑ een beetje	❑ tamelijk	❑ erg
Angstig 45	❑ niet	❑ een beetje	❑ tamelijk	❑ erg

Hartelijk dank voor het invullen van deze lijst! Mocht u vragen en/of opmerkingen hebben, dan kunt u die hieronder noteren.

TAAQOL

Questionnaire

from 16 onwards

Would you please answer the following questions first?

Are you male or female?	❑ male	❑ female	
What is your date of birth?	..... (month)	..... (day)	..... (year)
On what date was this questionnaire completed?	..... (month)	..... (day)	..... (year)

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Number: [_ _ _ _ _ _ _ _]

INSTRUCTIONS

Dear Sir, Madam,

The questions in this questionnaire relate to all kinds of different aspects of your health.
You can answer the questions by ticking the answer which is most applicable to you.

For example:

Did you have difficulty in the last month with

Walking up the stairs? X no ❑ a little ❑ some ❑ a lot

1

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

If there were problems with something, you are also asked how much that bothered you. So if you state that you had "a little" difficulty walking up the stairs, you can then indicate in the second part of the question how much that bothered you.

For example:

Did you have difficulty in the last month in

Walking up the stairs? ❑ no X a little ❑ some ❑ a lot

1

How much did that bother you?

❑ not at all ❑ a little X quite a lot ❑ very much

Did you have difficulty in the last month in

Walking up the stairs	❑ no	❑ a little	❑ some	❑ a lot	
1		**How much did that bother you?**			
		❑ not at all	❑ a little	❑ quite a lot	❑ very much
Bending over / kneeling / stooping	❑ no	❑ a little	❑ some	❑ a lot	
2		**How much did that bother you?**			
		❑ not at all	❑ a little	❑ quite a lot	❑ very much
Walking 500 yards (a couple of streets for example)	❑ no	❑ a little	❑ some	❑ a lot	
3		**How much did that bother you?**			
		❑ not at all	❑ a little	❑ quite a lot	❑ very much
Lifting (e.g. carrying shopping)	❑ no	❑ a little	❑ some	❑ a lot	
4		**How much did that bother you?**			
		❑ not at all	❑ a little	❑ quite a lot	❑ very much

Did you have difficulty in the last month with

Cutting paper with scissors	❑ no	❑ a little	❑ some	❑ a lot	
5		**How much did that bother you?**			
		❑ not at all	❑ a little	❑ quite a lot	❑ very much
Fastening the buttons of a blouse / shirt	❑ no	❑ a little	❑ some	❑ a lot	
6		**How much did that bother you?**			
		❑ not at all	❑ a little	❑ quite a lot	❑ very much
Opening a can	❑ no	❑ a little	❑ some	❑ a lot	
7		**How much did that bother you?**			
		❑ not at all	❑ a little	❑ quite a lot	❑ very much
Twisting the lid off a jar	❑ no	❑ a little	❑ some	❑ a lot	
8		**How much did that bother you?**			
		❑ not at all	❑ a little	❑ quite a lot	❑ very much

In the last month, did it happen that ...

You had difficulty concentrating on what others said? ❑ no ❑ a little ❑ some ❑ a lot

9

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

You had difficulty remembering things? ❑ no ❑ a little ❑ some ❑ a lot

10

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

You had difficulty thinking in a concentrated way? ❑ no ❑ a little ❑ some ❑ a lot

11

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

Your mind wandered? ❑ no ❑ a little ❑ some ❑ a lot

12

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

In the last month, how often did it happen that ...

You had difficulty getting to sleep? ❑ never ❑ occasionally ❑ often ❑ (almost) always

13

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

You slept restlessly ❑ never ❑ occasionally ❑ often ❑ (almost) always

14

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

You lay awake a lot at night? ❑ never ❑ occasionally ❑ often ❑ (almost) always

15

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

You had a good night's sleep ❑ (almost) always ❑ often ❑ occasionally ❑ never

16

If this was not always the case, how much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

In the last month, how often did you have

Back-ache ❑ never ❑ occasionally ❑ often ❑ (almost) always

17

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

Pain / tension in neck or shoulders ❑ never ❑ occasionally ❑ often ❑ (almost) always

18

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

Pain in joints / limbs ❑ never ❑ occasionally ❑ often ❑ (almost) always

19

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

Pain in muscles ❑ never ❑ occasionally ❑ often ❑ (almost) always

20

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

If you <u>needed it</u>, was it <u>possible</u> for you in the last month to ...

Talk to others in confidence ❑ often ❑ occasionally ❑ seldom ❑ never

21

If this was not always possible, how much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

Have a nice time with other people ❑ often ❑ occasionally ❑ seldom ❑ never

22

If this was not always possible, how much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

Visit friends ❑ often ❑ occasionally ❑ seldom ❑ never

23

If this was not always possible, how much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

Have a good talk with others ❑ often ❑ occasionally ❑ seldom ❑ never

24

If this was not always possible, how much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

In the last month, have you ...

Had difficulty with work, study or other day-to-day activities

25

❑ no ❑ a little ❑ some ❑ a lot

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

Done less work, studying or other day-to-day activities

26

❑ no ❑ a little ❑ some ❑ a lot

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

Had problems doing certain types of work, study or other day-to-day- activities

27

❑ no ❑ a little ❑ some ❑ a lot

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

Done work, study or other day-to-day activities less conscientiously

28

❑ no ❑ a little ❑ some ❑ a lot

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

Had less sex then previously

29

❑ no ❑ a little ❑ some ❑ a lot

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

Found sex less satisfying

30

❑ no ❑ a little ❑ some ❑ a lot

How much did that bother you?

❑ not at all ❑ a little ❑ quite a lot ❑ very much

In the last month, did you feel ...

Energetic 31	❑ no	❑ a little	❑ quite	❑ very
Tired 32	❑ no	❑ a little	❑ quite	❑ very
Fit 33	❑ no	❑ a little	❑ quite	❑ very
Exhausted quickly 34	❑ no	❑ a little	❑ quite	❑ very
Joyful 35	❑ no	❑ a little	❑ quite	❑ very
Sad 36	❑ no	❑ a little	❑ quite	❑ very
In good spirits 37	❑ no	❑ a little	❑ quite	❑ very
Angry 38	❑ no	❑ a little	❑ quite	❑ very
Worried 39	❑ no	❑ a little	❑ quite	❑ very
Gloomy 40	❑ no	❑ a little	❑ quite	❑ very
Aggressive 41	❑ no	❑ a little	❑ quite	❑ very
Happy 42	❑ no	❑ a little	❑ quite	❑ very
Short-tempered 43	❑ no	❑ a little	❑ quite	❑ very
Cheerful 44	❑ no	❑ a little	❑ quite	❑ very
Anxious 45	❑ no	❑ a little	❑ quite	❑ very

This is the end of the questionnaire.
Thank you for completing it!

WAYS OF COPING QUESTIONNAIRE (RESEARCH EDITION)

The Ways of Coping Questionnaire (WAYS) measures coping processes—not coping dispositions or styles. The WAYS can assess and identify thoughts and actions that individuals use to cope with the stressful encounters of everyday living. It measures coping processes, not coping dispositions or styles. In a variety of studies, researchers have used it to investigate the components and determinants of coping it identifies the processes people use in coping with stressful situations, can be completed in approximately in 10 minutes, between ages high school through adulthood.

The WAYS can help counselors work with clients to develop practical coping skills by evaluating their process, their strengths and weaknesses, and providing models of alternative coping mechanisms. The WAYS is excellent for research on coping and scales including: Confrontive Coping, Distancing, Self-Controlling, Seeking Social Support, Accepting Responsibility, Escape-Avoidance, Planful Problem Solving, and Positive Reappraisal.

Abbreviated Name: WAYS
Author(s): Susan Folkman and Richard S Lazarus
Purpose: To assess and identify thoughts and actions that individuals use to cope with the stressful encounters of every day living.
Population: Adult
Age Range : 18 and over
Type of Instrument: Coping
Mode of Administration

Rater:	Self-/ Group-administered
Time required:	10-15 minutes
Response Options:	5-point Likert scale
Scoring:	Scores by items
Score Direction:	Higher scores show better QoL

Number of Items: 66
Original Language: English

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Mind Garden Inc.
1690 Woodside Road, Suite 202
Redwood City, CA 94061 USA
Phone: +1 650-261-3500
Fax: +1 650-261-3505
E-mail: info@mindgarden.com

Dimensions covered by the questionnaire :

- Confronting coping
- Distancing
- Self-control
- Seeking social support
- Accepting responsability
- Escape-avoidance
- Planful problem solving
- Positive reappraisal

Key References:

1. Folkman S, Lazarus RS. Coping as a mediator of emotion. J Pers Soc Psychol. 1988;54(3):466-75.

There is widespread conviction among health care professionals that coping affects emotion. Yet theory and research have traditionally emphasized the effects of emotion on coping. The present research addresses this imbalance by evaluating the extent to which coping mediated emotions during stressful encounters in two Caucasian, community-residing samples. Subjects' recently experienced stressful encounters, the ways they coped with the demands of those encounters, and the emotions they experienced during two stages of those encounters were assessed repeatedly. The extent to which eight forms of coping mediated each of four sets of emotions was evaluated with a series of hierarchical regression analyses (of residuals). Coping was associated with changes in all four sets of emotions, with some forms of coping associated with increases in positive emotions and other forms associated with increases in negative emotions.

2. Folkman S, Chesnay M, Pollack L et al. Stress, control, coping and depressive mood in human immunodeficiency virus-positive and -negative men in San Francisco. Journal of Nervous and Mental Disease 1993;181:409-416

This study examined the relationship between stress, appraised control, and coping and depressive mood in 425 human immunodeficiency virus-positive and -negative gay men in San Francisco. Depressive mood was assessed by self-report in 1988 and 1989. Participants were also surveyed in 1989 on the stress in their lives, their appraised control over the stress, and the ways they coped. Depressive mood in 1988 and symptoms of human immunodeficiency virus disease in 1989 accounted for 50% of the variance in 1989 depressive mood; stress, appraised control, and coping accounted for an additional 10% of the variance in depressive mood in 1989. Path analysis indicated: stress appraised as controllable was associated with involvement coping, which in turn was associated with diminished depressive mood; stress associated with detachment was associated with increased depressive mood; and stress was also directly associated with increased depressive mood.

3. Folkman S, Chesnay MA, Cooke M et al. Care-giver burden in HIV-positive and HIV-negative partners of men with AIDS. Journal of Consulting and Clinical Psychology 1994;62:746-756

This study examines factors associated with caregiver burden in 82 HIV-positive (HIV+) and 162 HIV-negative (HIV-) partners of men with AIDS. We expected HIV+ caregivers to report more burden than HIV- caregivers because of the toll of their disease on their resources. HIV+ caregivers did report more burden and, compared with the HIV- caregivers, they were more religious or spiritual, had less income, and coped by using more positive reappraisal and cognitive escape-avoidance and by seeking social support. Comparisons of HIV+ caregivers with 61 HIV+ partners of healthy men indicated that most differences between HIV+ and HIV- caregivers were associated with HIV seropositivity rather than caregiving. However, of the variables associated with HIV seropositivity, only religiosity or spirituality contributed independently to burden in HIV+ caregivers, suggesting a relatively weak link between HIV seropositivity and caregiver burden. The model explained 62% of the variance in burden in HIV+ caregivers and 36% of the variance in HIV- caregivers.

WAYS OF COPING QUESTIONNAIRE (RESEARCH EDITION) SAMPLE ITEMS

WAYS OF COPING (WAYS)

(Folkman & Lazarus, 1988)

Instructions

To respond to the statements in this questionnaire, you must have a specific stressful NF1-related situation in mind. Take a few moments and think about the most stressful NF1-related situation that you have experienced in the *past week*.

By "stressful" we mean a situation that was difficult or troubling for you, either because you felt distressed about what happened, or because you had to use considerable effort to deal with the situation. The situation may have involved your family, your job, your friends, or something else important to you. Before responding to the statements, think about the details of this stressful situation, such as where it happened, who was involved, how you acted, and why it was important to you. While you may still be involved in the situation, or it could have already happened, it should be the most stressful situation that you experienced during the week.

As you respond to each of the statements, please keep this stressful situation in mind. **Read *each* statement carefully and indicate, by circling 0, 1, 2 or 3, to what extent you used it in the situation.**

0 = Does not apply or not used
1 = used somewhat
2 = used quite a bit
3 = used a great deal

Please try to respond to every question.

1. I just concentrated on what I had to do next.	0	1	2	3
2. I tried to analyze the problem in order to understand it better.	0	1	2	3
3. I turned to work or another activity to take my mind off things.	0	1	2	3
4. I felt that time would have made a difference – the only thing was to wait.	0	1	2	3
5. I bargained or compromised to get something positive from the situation.	0	1	2	3
6. I did something that I didn't think would work, but at least I was doing something.	0	1	2	3
7. I tired to get the person responsible to change his or her mind.	0	1	2	3
8. I talked to someone to find out more about the situation.	0	1	2	3
9. I criticized or lectured myself.	0	1	2	3
10. I tried not to burn bridges, but leave things open somewhat.	0	1	2	3
11. I hoped for a miracle.	0	1	2	3

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49. I knew what had to be done, so I doubled my efforts to make things work.	0	1	2	3
50. I refuse to believe that it had happened.	0	1	2	3
51. I promised myself that things would be different next time.	0	1	2	3
52. I came up with a couple of different solutions to the problem.	0	1	2	3
53. I accepted the situation, since nothing could be done.	0	1	2	3
54. I tried to keep my feelings about the problem from interfering with other things.	0	1	2	3
55. I wished that I could change what had happened or how I felt.	0	1	2	3
56. I changed something about myself.	0	1	2	3
57. I daydreamed or imagined a better time or place than the one I was in.	0	1	2	3
58. I wished that the situation would go away or somehow be over with.	0	1	2	3
59. I had fantasies or wishes about how things might turn out.	0	1	2	3
60. I prayed.	0	1	2	3
61. I prepared myself for the worst.	0	1	2	3
62. I went over in my mind what I would say or do.	0	1	2	3
63. I thought about how a person I admire would handle this situation and used that as a model.	0	1	2	3
64. I tried to see things from the other person's point of view.	0	1	2	3
65. I reminded myself how much worse things could be.	0	1	2	3
66. I jogged or exercised.	0	1	2	3

Scoring:

Raw Scores

To score the WAYS, add the raw score for each item on the scale to get the total score. There are four possible responses 0, 1, 2, and 3. These are also the weights that shoud be used to get the raw score. Note that not all 66 items are scaled.

# of items	Item in the scale	scale
6 ……..	6, 7, 17, 28, 34, 46……..	Confrontive Coping
6 ……..	12, 13, 15, 21, 41, 44 ……	Distancing
7 ……..	10, 14, 35, 43, 54, 62, 63 ……...	Self-Controlling
6 ……..	8, 18, 22, 31, 42, 45 ……...	Seeking Social Support
4 ……..	9, 25, 29, 51 ……...	Accepting Responsibility
8 ……..	11, 16, 33, 40, 47, 50, 58, 59 …….	Escape – Avoidance
6 …….. ….	1, 26, 39, 48, 49, 52 ……...	Planful Problem Solving
7 ……..	20, 23, 30, 36, 38, 56, 60 ……...	Positive Reappraisal

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Relative Scores:

To calculate the relative scores:

1. Calculate the average responses per scale by dividing the total raw score by the number of items in the scale. For example, if the raw score for Confrontive Coping is 15 then the average response is 2.5 because there are 6 items on this scale.
2. Sum the average responses per scale across all the scales.
3. Divide the average score for each scale (from 1) by the sum of the averages (from 2 above) for all 8 scales. This value is the relative score for the scale.

Relative Scores:

To calculate the relative scores:

1. Calculate the average responses per scale by dividing the total raw score by the number of items in the scale. For example, if the raw score for Confrontive Coping is 15 then the average response is 2.5 because there are 6 items on this scale.
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3. Divide the average score for each scale (from 1) by the sum of the averages (from 2 above) for all 8 scales. This value is the relative score for the scale.

WHO (FIVE) WELL-BEING INDEX

The Psychiatric Research Unit, Frederiksborg General Hospital, Hillerød, Denmark, is a WHO Collaborating Centre for Mental Health. Over the years, the WHO Collaborating Center at Frederiksborg General Hospital in Hillerød, Denmark, has worked with the concept of subjective quality of life as a dimension separate from social disability (*Bech P. Rating scales for psychopathology, health status and quality of life. A compendium on documentation in accordance with the DSM-III-R and WHO systems. Springer: Berlin 1993.*). The core items of subjective quality of life belong to the dimension of psychological well-being (positive mood, vitality and interest in things). In contrast to this, social disability includes the restriction of the ability to perform daily activities.

The WHO-Five Well-being Index was derived from a larger rating scale developed for a WHO project on quality of life in patients suffering from diabetes (*World Health Organization Regional Office for Europe and the International Diabetes Federation, Europe. Diabetes mellitus in Europe: a problem at all ages and in all countries. A model for prevention and self care. Meeting. Giorn Ital Diabetol 1990; 10 (suppl).*). During the first psychometric evaluation, 10 of the original 28 items were selected due to the homogeneity they had shown across the various European countries participating in this study (*Bech P, Gudex C, Staehr Johansen K. The WHO (Ten) Well-Being Index: Validation in Diabetes. Psychother Psychosom 1996; 65: 183-190.*).

Because positive psychological well-being has to include positively worded items only, these 10 items were then reduced to five items (WHO-Five) which still covered positive mood (good spirits, relaxation), vitality (being active and waking up fresh and rested), and general interests (being interested in things) (*Bech P. Quality of life in the psychiatric patient. London: Mosby-Wolfe 1998.& Bech P. Male depression: stress and aggression as pathways to major depression. In: Dawson A and Tylee A (eds.) Depression: Social and economic timebomb. London: BMJ Books 2001, pp 63-66.*).

Abbreviated Name: WHO-5 (or WBI-5)
Author(s): Per Bech
Purpose: To measure psychological well-being
Population: Adult
Age Range : 18 and over
Type of Instrument: Well-being
Mode of Administration:

Rater:	Self-administered
Time required:	2 minutes
Response Options:	6-point Likert scale from 0 (not present) to 5 (constantly present)
Scoring:	Global score: Minimum score: 0 / Maximum score: 100
Score Direction:	Higher scores show better QoL

Number of Items: 5
Original Language: Danish
Existing Translations : Albanian, Arab, Bulgarian, Dutch, English, Finnish, French, German, Hebrew, Hungarian, Icelandic, Japanese, Lithuanian, Norwegian, Persian (Farsi), Romanian, Russian, Spanish, Swedish, Turkish

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Contact for information and permission to use:

Per Bech
WHO Collaborating Centre
Psychiatric Research Unit
Frederiksborg General Hospital
DK-3400 Hillerød - DENMARK
Tel +45 48 29 33 18
Fax +45 48 26 38 77
E-mail: pebe@fa.dk

Dimensions covered by the questionnaire :

One (Psychological well-being)

Key References:

1. Bech P. Male depression: stress and aggression as pathways to major depression. In: Dawson A and Tylee A (eds.) Depression: Social and economic timebomb. London: BMJ Books 2001, pp 63-66.

2. Bech P, Olsen RL, Kjoller M, Rasmussen NK. Measuring well-being rather than the absence of distress symptoms: a comparison of the SF-36 Mental Health subscale and the WHO-Five Well-Being Scale. Int J Meth Psychiatr Res 2003; 85-91

The health status questionnaire Short-Form 36 (SF-36) includes subscales measuring both physical health and mental health. Psychometrically, the mental health subscale contains a mixture of mental symptoms and psychological well-being items, among other things, to prevent a ceiling effect when used in general population studies. Three of the mental health well-being items are also included in the WHO-Five well-being scale. In a Danish general population study, the mental health subscale was compared psychometrically with the WHO-Five in order to evaluate the ceiling effect. Tests for unidimensionality were used in the psychometric analyses, and the sensitivity of the scales in differentiating between changes in self-reported health over the past year has been tested. The results of the study on 9,542 respondents showed that, although the WHO-Five and the mental health subscale were found to be unidimensional, the WHO-Five had a significantly lower ceiling effect than the mental health subscale. The analysis identified the three depression symptoms in the mental health subscale as responsible for the ceiling effect. The WHO-Five was also found to be significantly superior to the mental health subscale in terms of its sensitivity in differentiating between those persons whose health had deteriorated over the past year and those whose health had not. In conclusion, the WHO-Five, which measures psychological well-being, reflects aspects other than just the absence of depressive symptoms.

3. Henkel V, Mergl R, Kohnen R, Maier W, Möller H-J, Hegerl U. Identifying depression in primary care: a comparison of different methods in a prospective cohort study. BMJ 2003; 326: 200-201.

Psykiatrisk Sygehus
FREDERIKSBORG AMT

WHO-Fem Trivselsindeks (1999 version)

Sæt venligst ved hvert af de 5 udsagn et kryds i det felt der kommer tættest på hvordan du har følt dig i de seneste to uger. Bemærk at et højere tal står for bedre trivsel.

Eksempel: Hvis du har følt dig *glad og i godt humør* i **lidt mere end halvdelen af tiden** i de sidste to uger, så sæt krydset i feltet med 3-tallet i øverste højre hjørne.

I de sidste 2 uger ...	Hele tiden	Det meste af tiden	Lidt mere end halv-delen af tiden	Lidt mindre end halvdelen af tiden	Lidt af tiden	På intet tidspunkt
1 .. har jeg været glad og i godt humør	5	4	3	2	1	0
2 .. har jeg følt mig rolig og afslappet	5	4	3	2	1	0
3 .. har jeg følt mig aktiv og energisk	5	4	3	2	1	0
4 .. er jeg vågnet frisk og udhvilet	5	4	3	2	1	0
5 .. har min dagligdag været fyldt med ting der interesserer mig	5	4	3	2	1	0

Pointberegning
For at beregne dit pointtal skal du lægge tallene i de afkrydsede felter sammen og gange summen med fire.
Du får nu et tal mellem 0 og 100. Jo flere points jo højere trivsel. Hvis dit tal er 50 eller mindre, er du i en risikozone for stress eller depression.

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Interpretation:

Det anbefales at bruge MDI (Major Depression Inventory), hvis råscoren ligger under 13 eller hvis patienten har afkrydset 1 eller 0 på et enkelt item. En score under 13 indikerer dårlig trivsel og man bør undersøge, om der er tale om depression.

Ændringer:

For at se, om der sker ændringer i patientens trivsel, går man ud fra procentvis ændring af scores. En forskel på 10% indikerer således en signifikant ændring (ref. John Ware, 1995).

Psychiatric Research Unit
WHO Collaborating Centre in Mental Health

WHO (Five) Well-Being Index (1998 version)

Please indicate for each of the five statements which is closest to how you have been feeling over the last two weeks. Notice that higher numbers mean better well-being.

Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box with the number 3 in the upper right corner.

	Over the last two weeks	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
1	**I have felt cheerful and in good spirits**	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
2	**I have felt calm and relaxed**	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
3	**I have felt active and vigorous**	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
4	**I woke up feeling fresh and rested**	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
5	**My daily life has been filled with things that interest me**	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

Scoring:

The raw score is calculated by totalling the figures of the five answers. The raw score ranges from 0 to 25, 0 representing worst possible and 25 representing best possible quality of life.

To obtain a percentage score ranging from 0 to 100, the raw score is multiplied by 4. A percentage score of 0 represents worst possible, whereas a score of 100 represents best possible quality of life.

Interpretation:

It is recommended to administer the Major Depression (ICD-10) Inventory if the raw score is below 13 or if the patient has answered 0 to 1 to any of the five items. A score below 13 indicates poor wellbeing and is an indication for testing for depression under ICD-10.

Monitoring change:

In order to monitor possible changes in wellbeing, the percentage score is used. A 10% difference indicates a significant change (ref. John Ware, 1995).

WHO QUALITY OF LIFE ASSESSMENT

The Constitution of the World Health Organization (WHO) defines health as "A state of complete physical, mental, and social well-being not merely the absence of disease . . .". It follows that the measurement of health and the effects of health care must include not only an indication of changes in the frequency and severity of diseases but also an estimation of well being and this can be assessed by measuring the improvement in the quality of life related to health care. Although there are generally satisfactory ways of measuring the frequency and severity of diseases this is not the case in so far as the measurement of well being and quality of life are concerned. WHO, with the aid of 15 collaborating centres around the world, has therefore developed two instruments for measuring quality of life (the WHOQOL-100 and the WHOQOL-BREF), that can be used in a variety of cultural settings whilst allowing the results from different populations and countries to be compared. These instruments have many uses, including use in medical practice, research, audit, and in policy making.

WHO defines Quality of Life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.

The WHOQOL-BREF instrument comprises 26 items, which measure the following broad domains: physical health, psychological health, social relationships, and environment. This version is available in approximately 19 different language versions. The WHOQOL-BREF is a shorter version of the original instrument that may be more convenient for use in large research studies or clinical trials.

Abbreviated Name: WHOQOL & WHOQOL-BREF
Author(s): The WHOQOL Group, WHO, Geneva
Purpose: To assess individuals' perceptions on the quality of their life
Population: Adult
Age Range : 18 and over
Type of Instrument: Quality of life
Mode of Administration:

Rater:	Self-/ Interviewer-administered
Time required:	WHOQOL: 10-20 minutes for the self-administered version, up to 60 minutes for the interviewer-administered version WHOQOL-BREF: 5 minutes for self-administration, 15-20 minutes for interviewer-administration
Response Options:	Likert scale
Scoring:	Global score Scores by dimension
Score Direction:	Higher scores show better QoL
Weighting:	Yes

Number of Items: WHOQOL: 100 items / WHOQOL-BREF: 26 items
Original Language: English
Existing Translations : Arabic, Bulgarian, Chinese, Croatian, Czech, Danish, Dutch, Estonian, French, German, Greek, Hungarian, Hebrew, Hindi, Italian, Japanese, Kannada, Korean, Lithuanian, Malay, Norwegian, Polish, Portuguese, Russian, Shona, Slovakian, Spanish, Swedish, Tamil, Thai, Turkish, Urdu, Zambia

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Contact for information and permission to use:

WHOQOL
Department of Mental Health
World Health Organization
1211 Geneva 27, Switzerland
Tel: +41 22 791 36 34
Fax: + 41 22 791 41 60
E-mail:whoqol@who.ch

Dimensions covered by the questionnaire :

WHOQOL-100 (4 items per facet):

- Physical (3 facets)
- Psychological (5 facets)
- Level of independance (4 facets)
- Social relationships (3 facets)
- Environment (8 facets)
- Spirituality/religion/personal beliefs (1 facet)
- + 4 general QOL items

WHOQOL-BREF (1 item per facet of the WHOQOL-100):

- Physical (3 items)
- Psychological (5 items)
- Level of independance (4 items)
- Social relationships (3 items)
- Environment (8 items)
- Spirituality/religion/personal beliefs (1 items)
- + 2 overall QOL and general health items

Key References:

1. The WHOQOL Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. Psychol Med 1998;28(3):551-8

Background: The paper reports on the development of the WHOQOL-BREF, an abbreyiated version of the WHOQOL-100 quality of life assessment. Method: The WHOQOL-BREF was derived from data collected using the WHOQOL-100. It produces scores for four domains related to quality of life: physical health, psychological, social relationships and environment. It also includes one facet on overall quality of life and general health. Results: Domain scores produced by the WHOQOL-BREF correlate highly (0.89 or above) with WHOQOL-100 domain scores (calculated on a four domain structure). WHOQOL-BREF domain scores demonstrated good discriminant validity, content validity, internal consistency and test-retest reliability. Conclusion: These data suggest that the WHOQOL-BREF provides a valid and reliable alternative to the assessment of domain profiles using the WHOQOL-100. It is envisaged that the WHOQOL-BREF will be most useful in studies that require a brief assessment of quality of life, for example, in large epidemiological studies and clinical trials where quality of life is of interest. In addition, the WHOQOL-BREF may be of use to health professionals in the assessment and evaluation of treatment efficacy.

2. Szabo S (on behalf of the WHOQOL group). The World Health Organization Quality of Life (WHOQOL) assessment instrument. In: Bert Spilker (Ed). Quality of Life and Pharmacoeconomics in Clinical Trials (2nd edition). Philadelphia, New York, Lippincott-Raven Publishers, 1996

3. The WHOQOL Group. The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties. Soc Sci Med. 1998 Jun;46(12):1569-85.

This paper reports on the field testing, empirical derivation and psychometric properties of the World Health Organisation Quality of Life assessment (the WHOQOL). The steps are presented from the development of the initial pilot version of the instrument to the field trial version, the so-called WHOQOL-100. The instrument has been developed collaboratively in a number of centres in diverse cultural settings over several years; data are presented on the performance of the instrument in 15 different settings worldwide.

4. The WHOQOL Group. The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. Soc Sci Med. 1995 Nov;41(10):1403-9.

This paper describes the World Health Organization's project to develop a quality of life instrument (the WHOQOL). It outlines the reasons that the project was undertaken, the thinking that underlies the project, the method that has been followed in its development and the current status of the project. The WHOQOL assesses individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It has been developed collaboratively in several culturally diverse centres over four years. Piloting of the WHOQOL on some 4500 respondents in 15 cultural settings has been completed. On the basis of this data the revised WHOQOL Field Trial Form has been finalized, and field testing is currently in progress. The WHOQOL produces a multi-dimensional profile of scores across six domains and 24 sub-domains of quality of life.

5. The WHOQOL Group. The Development of the WHO Quality of Life Assessment Instrument (The WHOQOL) in Orley J and Kuyken W (eds). Quality of Life Assessment: International Perspectives. Berlin. Springer-Verlag. 1994; 41-57

6. The WHOQOL Group. Study protocol for the World Health Organization project to develop a Quality of Life assessment instrument (WHOQOL). Qual Life Res. 1993 Apr;2(2):153-9.

The World Health Organization (WHO) has undertaken a project to develop an instrument (the WHOQOL) for measuring quality of life. Quality of life is defined as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment. The instrument will be developed in the framework of a collaborative project involving numerous centres in different cultural settings. In addition, it will have proven psychometric properties of validity, responsiveness and reliability and will be sensitive to the cultural setting in which it is applied, whilst maintaining comparability of scores across different cultural settings. This paper outlines the characteristics of the planned instrument and the study protocol governing work on its development. To date steps 1 through 5 have been completed and work is progressing on step 6. It is anticipated that the instrument will be available for piloting in July 1993 and a final version available for use in June 1994.

Field Trial

WHOQOL-100

February 1995

THE 100 QUESTIONS WITH RESPONSE SCALES

DIVISION OF MENTAL HEALTH

WORLD HEALTH ORGANIZATION

GENEVA

Field Trial

WHOQOL-100

February 1995

The WHOQOL-100 has been developed from an extensive pilot test of some 300 WHOQOL questions in 15 centres around the world. Data from this pilot testing on over 4.500 subjects enabled the 100 best questions to be selected according to set criteria.

These questions respond to the definition of Quality of Life as *individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.*

These questions represent the finalized version of the WHOQOL-100 to be used for field trials. It is a generic English version and should never be used as it stands, nor just be translated. Versions suitable for use in the different populations involved in the pilot study, are available from the listed field trial centres. These versions are constructed by taking the corresponding 100 questions and response scales exactly as they stood in the language version that was used in the pilot test. (It should be noted that some variations exist even between the versions from the three English language centres.)

Centres wishing to develop a new language or cultural version, must follow the protocol for new centres under the supervision of the Division of Mental Health, WHO, Geneva, and as mentioned above must never just make a direct translation or an unsupervised adaptation of the WHOQOL-100.

DIVISION OF MENTAL HEALTH
WORLD HEALTH ORGANIZATION
GENEVA
1995

Field trial

WHOQOL-100

February 1995

Instructions

This questionnaire asks how you feel about your quality of life, health, and other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the **last two weeks**.

For example, thinking about the last two weeks, a question might ask:

How much do you worry about your health?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

You should circle the number that best fits how much you have worried about your health over the last two weeks. So you would circle the number 4 if you worried about your health "Very much", or circle number 1 if you have worried "Not at all" about your health. Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

Thank you for your help

The following questions ask about **how much** you have experienced certain things in the last two weeks, for example, positive feelings such as happiness or contentment. If you have experienced these things an extreme amount circle the number next to "An extreme amount". If you have not experienced these things at all, circle the number next to "Not at all". You should circle one of the numbers in between if you wish to indicate your answer lies somewhere between "Not at all" and "Extremely". Questions refer to the last two weeks.

F1.2 (F1.2.1)* Do you worry about your pain or discomfort?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F1.3 (F1.2.3) How difficult is it for you to handle any pain or discomfort?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F1.4 (F1.2.5) To what extent do you feel that (physical) pain prevents you from doing what you need to do?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F2.2(F2.1.3) How easily do you get tired?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F2.4 (F2.2.4) How much are you bothered by fatigue?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F3.2 (F4.1.3) Do you have any difficulties with sleeping?

None at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F3.4 (F4.2.3) How much do any sleep problems worry you?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F4.1 (F6.1.2) How much do you enjoy life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

* The numbers in brackets refer to the number of the question in the pilot question pool. National versions must be constructed using that same question taken from national version of the pilot questionnaire.

F4.3 (F6.1.4) How positive do you feel about the future?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F4.4 (F6.1.6) How much do you experience positive feelings in your life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F5.3 (F7.1.6) How well are you able to concentrate?

Not at all	Slightly	Moderately	Very well	Extremely
1	2	3	4	5

F6.1 (F8.1.1) How much do you value yourself?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F6.2 (F8.1.3) How much confidence do you have in yourself?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F7.2 (F9.1.3) Do you feel inhibited by your looks?

Not at all	Slightly	Moderately	Very much	Extremely
1	2	3	4	5

F7.3 (F9.1.4) Is there any part of your appearance which makes you feel uncomfortable?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F8.2 (F10.1.3) How worried do you feel?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F8.3 (F10.2.2) How much do any feelings of sadness or depression interfere with your everyday functioning?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F8.4 (F10.2.3) How much do any feelings of depression bother you?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F10.2 (F12.1.3)To what extent do you have difficulty in performing your routine activities?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F10.4 (F12.2.4) How much are you bothered by any limitations in performing everyday living activities?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F11.2 (F13.1.3) How much do you need any medication to function in your daily life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F11.3 (F13.1.4) How much do you need any medical treatment to function in your daily life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F11.4 (F13.2.2) To what extent does your quality of life depend on the use of medical substances or medical aids?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F13.1 (F17.1.3) How alone do you feel in your life?

Not at all	Slightly	Moderately	Very much	Extremely
1	2	3	4	5

F15.2 (F3.1.2) How well are your sexual needs fulfilled?

Not at all	Slightly	Moderately	Very much	Extremely
1	2	3	4	5

F15.4 (F3.2.3) Are you bothered by any difficulties in your sex life

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F16.1 (F20.1.2) How safe do you feel in your daily life?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F16.2 (F20.1.3) Do you feel you are living in a safe and secure environment?

Not at all	Slightly	Moderately	Very much	Extremely
1	2	3	4	5

F16.3 (F20.2.2) How much do you worry about your safety and security?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F17.1 (F21.1.1) How comfortable is the place where you live?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F17.4 (F21.2.4)How much do you like it where you live?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F18.2 (F23.1.5) Do you have financial difficulties?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F18.4 (F23.2.4) How much do you worry about money?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F19.1 (F24.1.1) How easily are you able to get good medical care?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F21.3 (F26.2.2) How much do you enjoy your free time?

Not at all	A little	Moderately	Very much	An extreme amount
1	2	3	4	5

*F22.1 (F27.1.2) How healthy is your physical environment?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F22.2 (F27.2.4) How concerned are you with the noise in the area you live in?

Not at all	A little	Moderately	Very much	An extreme amount
1	2	3	4	5

F23.2 (F28.1.4) To what extent do you have problems with transport?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F23.4 (F28.2.3) How much do difficulties with transport restrict your life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

* Note: These questions were inappropriately given a capacity response scale in the pilot version. They are to be given an intensity scale in the WHOQOL-100.

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks, for example activities of daily living such as washing, dressing or eating. If you have been able to do these things completely, circle the number next to "Completely". If you have not been able to do these things at all, circle the number next to "Not at all". You should circle one of the numbers in between if you wish to indicate your answer lies somewhere between "Not at all" and "Completely". Questions refer to the last two weeks.

F2.1 (F2.1.1) Do you have enough energy for everyday life?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F7.1 (F9.1.2) Are you able to accept your bodily appearance?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F10.1 (F12.1.1)To what extent are you able to carry out your daily activities?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F11.1 (F13.1.1)How dependent are you on medications?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F14.1 (F18.1.2)Do you get the kind of support from others that you need?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F14.2 (F18.1.5)To what extent can you count on your friends when you need them?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F17.2 (F21.1.2)To what degree does the quality of your home meet your needs?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F18.1 (F23.1.1)Have you enough money to meet your needs?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F20.1 (F25.1.1)How available to you is the information that you need in your day-to-day life?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F20.2 (F25.1.2) To what extent do you have opportunities for acquiring the information that you feel you need?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F21.1 (F26.1.2)To what extent do you have the opportunity for leisure activities?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F21.2 (F26.1.3)How much are you able to relax and enjoy yourself?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F23.1 (F28.1.2)To what extent do you have adequate means of transport?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

The following questions ask you to say how **satisfied, happy or good** you have felt about various aspects of your life over the last two weeks . For example, about your family life or the energy that you have. Decide how satisfied or dissatisfied you are with each aspect of your life and circle the number that best fits how you feel about this. Questions refer to the last two weeks.

G2 (G2.1) How satisfied are you with the quality of your life?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

G3 (G2.2) In general, how satisfied are you with your life?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

G4 (G2.3) How satisfied are you with your health?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F2.3 (F2.2.1) How satisfied are you with the energy that you have?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F3.3 (F4.2.2) How satisfied are you with your sleep?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F5.2 (F7.2.1) How satisfied are you with your ability to learn new information?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F5.4 (F7.2.3) How satisfied are you with your ability to make decisions?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F6.3 (F8.2.1) How satisfied are you with yourself?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F6.4 (F8.2.2) How satisfied are you with your abilities?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F7.4 (F9.2.3) How satisfied are you with the way your body looks?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F10.3 (F12.2.3)How satisfied are you with your ability to perform your daily living activities?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F13.3 (F17.2.3)How satisfied are you with your personal relationships?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F15.3 (F3.2.1) How satisfied are you with your sex life?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F14.3 (F18.2.2)How satisfied are you with the support you get from your family?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F14.4 (F18.2.5)How satisfied are you with the support you get from your friends?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F13.4 (F19.2.1)How satisfied are you with your ability to provide for or support others?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F16.4 (F20.2.3)How satisfied are you with your physical safety and security?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F17.3 (F21.2.2)How satisfied are you with the conditions of your living place?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F18.3 (F23.2.3)How satisfied are you with your financial situation?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F19.3 (F24.2.1)How satisfied are you with your access to health services?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F19.4(F24.2.5)How satisfied are you with the social care services?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F20.3 (F25.2.1)How satisfied are you with your opportunities for acquiring new skills?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F20.4 (F25.2.2)How satisfied are you with your opportunities to learn new information?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F21.4 (F26.2.3)How satisfied are you with the way you spend your spare time?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F22.3 (F27.2.1)How satisfied are you with your physical environment (e.g. pollution, climate, noise, attractiveness)?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F22.4 (F27.2.3)How satisfied are you with the climate of the place where you live?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F23.3 (F28.2.2)How satisfied are you with your transport?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F13.2 (F17.2.1)Do you feel happy about your relationship with your family members?

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very happy
1	2	3	4	5

G1 (G1.1) How would you rate your quality of life?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

F15.1 (F3.1.1) How would you rate your sex life?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

F3.1 (F4.1.1) How well do you sleep?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

F5.1 (F7.1.3) How would you rate your memory?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

F19.2 (F24.1.5)How would you rate the quality of social services available to you?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

The following questions refer to **how often** you have felt or experienced certain things, for example the support of your family or friends or negative experiences such as feeling unsafe. If you have not experienced these things at all in the last two weeks, circle the number next to the response "never". If you have experienced these things, decide how often and circle the appropriate number. So for example if you have experienced pain all the time in the last two weeks circle the number next to "Always". Questions refer to the last two weeks.

F1.1 (F1.1.1) How often do you suffer (physical) pain?

Never	Seldom	Quite often	Very often	Always
1	2	3	4	5

F4.2 (F6.1.3) Do you generally feel content?

Never	Seldom	Quite often	Very often	Always
1	2	3	4	5

F8.1 (F10.1.2) How often do you have negative feelings, such as blue mood, despair, anxiety, depression?

Never	Seldom	Quite often	Very often	Always
1	2	3	4	5

The following questions refer to any "**work**" that you do. Work here means any major activity that you do. This includes voluntary work, studying full-time, taking care of the home, taking care of children, paid work or unpaid work. So work, as it is used here, means the activities you feel take up a major part of your time and energy. Questions refer to the last two weeks.

F12.1 (F16.1.1)Are you able to work?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F12.2 (F16.1.2)Do you feel able to carry out your duties?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F12.4 (F16.2.1)How satisfied are you with your capacity for work?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F12.3 (F16.1.3)How would you rate your ability to work?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

The next few questions ask about **how well you were able to move around**, in the last two weeks. This refers to your physical ability to move your body in such a way as to allow you to move about and do the things you would like to do, as well as the things that you need to do.

F9.1 (F11.1.1) How well are you able to get around?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

F9.3 (F11.2.2) How much do any difficulties in mobility bother you?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F9.4 (F11.2.3) To what extent do any difficulties in movement affect your way of life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F9.2 (F11.2.1) How satisfied are you with your ability to move around?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

The following few questions are concerned with **your personal beliefs**, and how these affect your quality of life. These questions refer to religion, spirituality and any other beliefs you may hold. Once again these questions refer to the last two weeks.

F24.1 (F29.1.1)Do your personal beliefs give meaning to your life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F24.2 (F29.1.3)To what extent do you feel your life to be meaningful?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F24.3 (F29.2.2)To what extent do your personal beliefs give you the strength to face difficulties?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F24.4 (F29.2.3)To what extent do your personal beliefs help you to understand difficulties in life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

ABOUT YOU

What is your gender?

Male
Female

What is your date of birth?

_____/_____/_____
DAY / MONTH / YEAR

What is highest education you received?

Primary school
Secondary school
University
Post-graduate

What is your marital status?

Single
Married
Living as married
Separated
Divorced
Widowed

How is your health? (G1.2)**

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

What health problems do you have at the moment? (TICK NEXT TO THOSE THAT APPLY TO YOU)

Heart trouble
High blood pressure
Arthritis or Rheumatism
Cancer
Emphysema or chronic bronchitis
Diabetes
A cataract
Stroke
Broken or fractured bone
Chronic nervous or emotional problems
Chronic foot trouble (bunions, ingrowing toenails)
Rectal growth or rectal bleeding
Parkinson's disease
Other (please describe)

Are you currently ill?

If yes, what is your diagnosis? _____

** This question was originally in the body of rated questions in the pilot questionnaire.

THE WORLD HEALTH ORGANIZATION QUALITY OF LIFE (WHOQOL) -BREF

The World Health Organization Quality of Life (WHOQOL)-BREF

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WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Do you have any comments about the assessment?

_____

_____

[The following table should be completed after the interview is finished]

		Equations for computing domain scores	Raw score	Transformed scores*	
				4-20	0-100
27.	**Domain 1**	(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18 ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐	a. =	b:	c:
28.	**Domain 2**	Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26) ☐ + ☐ + ☐ + ☐ + ☐ + ☐	a. =	b:	c:
29.	**Domain 3**	Q20 + Q21 + Q22 ☐ + ☐ + ☐	a. =	b:	c:
30.	**Domain 4**	Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25 ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐	a. =	b:	c:

* See Procedures Manual, pages 13-15

WORK LIMITATIONS QUESTIONNAIRE

The Work Limitations Questionnaire (WLQ) is a 25-item, self-administered questionnaire measuring the degree to which health problems interfere with ability to perform job roles. It was designed for assessing groups of individuals ("respondents") who are currently employed. The WLQ indicates the degree to which health problems interfere with specific aspects of job performance (on-the-job disability), and the productivity impact of these work limitations.

Abbreviated Name: WLQ
Author(s): Debra Lerner & Benjamin C. Amick
Purpose: To assess the on-the-job impact of chronic health problems and/or treatment ("work limitations")
Population: Adult
Age Range : Working population
Type of Instrument: Disability / Physical functioning
Mode of Administration:

Rater:	Self-administered
Time required:	10 minutes
Response Options:	Likert scale
Scoring:	Global score
	Scores by dimension
Score Direction:	Lower scores show better QoL
Weighting:	Yes

Number of Items: 25
Original Language: English
Existing Translations : Spanish, French

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Contact for information and permission to use:

Debra Lerner, Ph.D
The Health Institute
New England Medical Center
750 Washington Street
NEMC #345, Boston, MA 02111, USA

Dimensions covered by the questionnaire :

- Time management (5 items)
- Physical demands (6 items)
- Mental-Interpersonal demands (9 items)
- Output demands (5 items)

Key References:

1. Lerner D, Amick BC 3rd, Rogers WH, Malspeis S, Bungay K, Cynn D. The Work Limitations Questionnaire. Med Care 2001;39:72-85.

Objective: The objective of this work was to develop a psychometrically sound questionnaire for measuring the on-the-job impact of chronic health problems and/or treatment ("work limitations"). Research Design: Three pilot studies (focus groups, cognitive interviews, and an alternate forms test) generated candidate items, dimensions, and response scales. Two field trials tested the psychometric performance of the questionnaire (studies 1 and 2). To test recall error, study 1 subjects were randomly assigned to 2 different questionnaire groups, a questionnaire with a 4-week reporting period completed once or a 2-week version completed twice. Responses were compared with data from concurrent work limitation diaries (the gold standard). To test construct validity, we compared questionnaire scores of patients with those of healthy job-matched control subjects. Study 2 was a cross-sectional mail survey testing scale reliability and construct validity. Subjects: The study subjects were employed individuals (18-64 years of age) from several chronic condition groups (study 1, n = 48; study 2, n = 121) and, in study 1, 17 healthy matched control subjects. Measures: Study 1 included the assigned questionnaires and weekly diaries. Study 2 included the new questionnaire, SF-36, and work productivity loss items. Results: In study 1, questionnaire responses were consistent with diary data but were most highly correlated with the most recent week. Patients had significantly higher (worse) limitation scores than control subjects. In study 2, 4 scales from a 25-item questionnaire achieved Cronbach alphas of > or = 0.90 and correlated with health status and self-reported work productivity in the hypothesized manner (P < or = 0.05). Conclusions: With 25 items, 4 dimensions (limitations handling time, physical, mental-interpersonal, and output demands), and a 2-week reporting period, the Work Limitations Questionnaire demonstrated high reliability and validity.

The Work Limitations Questionnaire (WLQ)[§]

The WLQ is a 25-item, self-administered questionnaire measuring the degree to which health problems interfere with ability to perform job roles. It was designed for assessing groups of individuals ("respondents") who are currently employed. The WLQ indicates the degree to which health problems interfere with specific aspects of job performance (on-the-job disability), and the productivity impact of these work limitations.

The WLQ fills an important gap in measurement. Previously, the work consequences of health problems have been quantified in population-based and clinical studies, using a variety of indicators and measurement approaches. Rates of employment and job loss, and post-illness return to work are among the most frequently used outcome indicators. The social role disability scales contained within several well-known health status questionnaires have been another source of valuable information. Typically, they measure partial and total decrements in ability to perform paid and unpaid (e.g., housework) roles. Within the private sector, rates of employee work absences are widely used to indicate the impact of health in the workplace and, specifically, to estimate productivity loss due to missed work time. The WLQ addresses the impact on health problems on-the-job. Unlike other survey instruments, it asks respondents to report on their limitations handling specific types of job demands. The WLQ is more comprehensive than other comparable scales and indicators, and it provides the user with a greater breadth and depth of information.

The WLQ items ask respondents to rate their level of difficulty (or, on one scale, their level of ability) to perform 25 specific job demands. These demands have four defining features: 1) a wide range of jobs in the US include these demands; 2) a wide variety of physical and emotional health problems can make it difficult to perform these demands effectively; 3) the demands are considered important to the job from the perspective of job incumbents; and 4) losses in individual work productivity are frequently related to the degree to which these demands are performed.

Responses to the 25 items are combined into four work limitation scales. These capture the multi-dimensionality of job roles (most jobs involve numerous tasks). They also reflect an important characteristic of many health problems, which is that they may result in limitations in performing some activities but not others.

The WLQ's Time Management scale (Question 1) contains five items addressing difficulty performing a job's time and scheduling demands. The six-item Physical Demands scale (Question 2) covers a person's ability to perform job tasks that involve bodily strength, movement, endurance, coordination and flexibility. The Mental/Interpersonal Demands Scale (Questions 3 and 4) has nine items. Six items pertain to difficulty performing cognitive job tasks and/or tasks involving the processing of sensory information. Three items address a person's problems interacting with people on-the-job. The fourth scale is the Output Demands scale (Question 5). It contains five items concerning decrements in a person's ability to meet demands for quantity, quality, and timeliness of completed work.

While comprehensive, the WLQ is brief and easy to administer. It is usually self-administered by respondents. A phone version is also available. It has been translated into several languages. The average amount of time it takes to complete the WLQ by self-administration is 5-10 minutes.

[§] Work Limitations Questionnaire, 1998, The Health Institute; Debra Lerner, Ph.D.; Benjamin C. Amick III, Ph.D.; and GlaxoWellcome, Inc. All Rights Reserved.

Following a 4-year development process, the WLQ's became available for use in 1999. The results of several studies of the WLQ's psychometric performance have provided evidence of its reliability, validity, and precision.

The following sections describe the initial steps in the WLQ's development, results of psychometric tests and considerations for users. Details of several of these studies are provided in Medical Care (39:1,pp. 72-85, 2001).

To enhance our understanding of the on-the-job impact of health problems our initial studies included patient and population-based samples. Patients involved in these initial studies represented several different chronic condition groups (e.g., respiratory diseases including asthma, gastrointestinal disorders including Crohn's Disease and liver disease, mental illnesses including depression and generalized anxiety, epilepsy, chronic daily headache syndrome, and rheumatoid arthritis. Parallel studies have included patients with heart disease, low back pain, and occupational injuries (see Spine, 25:3152-3160, 2000).

Content Validity

Content validity tests assure that the questions included in a survey instrument represent the attributes of the concept that is purportedly being measured. The first item pool for the WLQ was developed by: 1) reviewing the work classification literature, which identified categories of job and occupational demands relevant to a large number of jobs in the United States; 2) convening a series of four focus groups consisting of employed patients who had one of the aforementioned chronic conditions; 3) conducting cognitive interviews with employed patients; and, 4) conducting a review of the candidate items by a physician expert panel.

Each focus group participant was asked to describe his/her job demands, health status, a "good" health day and a "bad" health day, and how health problems and medical care affected the performance of specific job demands. This process, involving 18 participants, generated 70 job-demand-level limitation items and 7 candidate dimensions (i.e., categories of work limitations).

The next step involved evaluating questionnaire content using cognitive interview methods. Approximately 40 employed, chronically ill patients participated. Items were rated for comprehensibility, ease of recalling information necessary to respond and ease of formulating a response. Individual interviews were conducted with each person. Each participant was given a mock questionnaire and asked to read each question (aloud or silently), paraphrase the question in his or her own words, and answer the question while thinking aloud. At the end of the interview, participants were given the opportunity to comment further on the questions and suggest new items. In addition to assessing content validity, the process can aid in identifying problems related to item reliability and systematic bias.

Items were rated for their comprehensibility, redundancy, relevance to job requirements, relevancy to the illness' symptoms, and ease of responding. As a result, 32 items failed, and 38 passed. Of the passing items, 25 were revised slightly and 2 items were added. Thus, 40 items were retained.

Next, a multidisciplinary physician panel reviewed this 40-item pool. Items were evaluated for "clinical sensibility". "Clinical sensibility" means the degree to which performance of the demands could be regarded as an outcome of certain chronic, disabling illnesses. This process resulted in minor modifications.

Item and Scale Reliability

An assessment, conducted at two different work sites, included 15 pairs of coworkers. The coworkers in each pair were matched on job and employer. However, one of the coworkers in each pair (the case) had at least one chronic condition. The control coworker had no chronic conditions. Each pair was blinded to the fact that health status was an eligibility criterion. This test assessed whether employed individuals could report reliably on their job demands, and whether health status biased results. Participants completed a questionnaire that asked if the job demands, which were mentioned in the WLQ items, were present or absent. During the period addressed in the survey, an expert observer (an ergonomist and trained assistants) went to each work site, at different times, and observed people assigned to the same types of jobs as the participants. The observers assessed the presence or absence of the job demands. This triangulation method permits assessment of inter-rater reliability. Results indicated adequate agreement among raters. Agreement was higher for the items addressing mental work demands vs. those measuring physical work demands. These results led to modifications of some physical demand items.

Intra-rater reliability and recall error was assessed in a subsequent study. This study involved the evaluation of 3 candidate response scales. Approximately 40 employed, chronically ill patients participated. Nine separate work limitation items were embedded in three different question stem/response scale formats. Thus, each participant answered the 9 questions 3 times, though each question was posed slightly differently each time. When responses to each set of three questions were compared, they agreed with each other in 79% of the comparisons. However, one form performed worse than the other two. Specifically, responses to questions on one of the forms were mismatched more frequently with those on the other two forms. After debriefing participants, we determined that one of the question stem/response option formats had slightly better accuracy (less recall error). The current WLQ reflects the results of this test.

A 48-item WLQ was assessed in a mail-out/mail-back survey. It included the 40-item pool and 8 new items suggested by the interactions with study participants. The sample included 121 employed patients within three illness groups: rheumatoid arthritis, chronic daily headache syndrome, and epilepsy. Cronbach's statistics were between the recommended levels of .70 and .90 for all items or slightly higher. Item-to-total scale score correlation coefficients, corrected for overlap, were greater than the minimum acceptable .20 level and exceeded the more stringent.40 level. Items within each scale were more highly correlated with their assigned scale's score than with the other scales' scores (scaling success rate = 100% for each scale).

A shorter 25 item WLQ was produced by retaining the best performing items. Psychometric test results were excellent. The WLQ's scale structure has been replicated in several other samples (e.g., patients with depression, patients with osteoarthritis, short-term disability claimants with low back pain, and work site samples).

Construct Validity

Construct validity refers to the degree to which scores obtained from an item or scale correspond to scores obtained from tools measuring a parallel or related concept. Several tests established the relationship of WLQ scores to measures of functional health status. The WLQ was compared to the SF-36 role limitation scales (role/physical and role/emotional). In 7 out of 8 multiple linear regressions (adjusted for age and gender), the WLQ scales were related significantly to the scales (n=121).

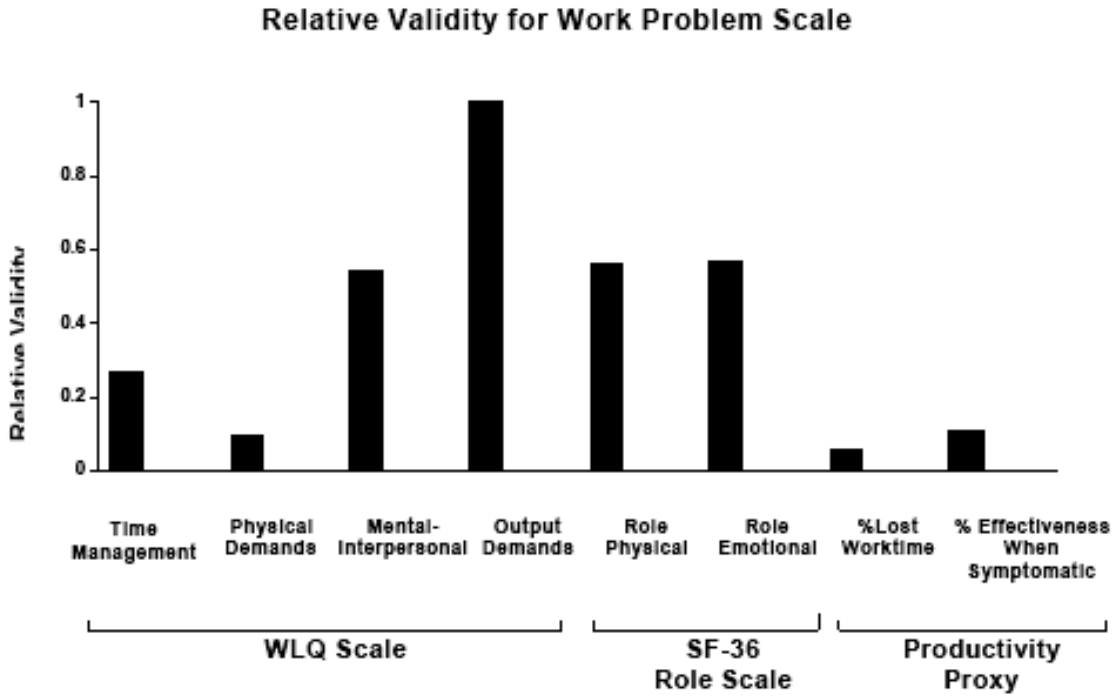
Work Limitations Questionnaire Scaling Test Results

Scale	Items n	Mean*	(SD)	% Floor	% Ceiling	Scale Alpha	Range of Item-to-Total Corr	% Scaling Success[a]
48-Item Work Limitations Questionnaire								
• Time Demands	9	32.5	27.4	10.1	0	.89	.51-.77	97.2
• Physical Demands	11	32.4	34.5	19.3	1.8	.96	.72-.88	100
• Mental Demands	14	32.9	25.0	6.4	0	.94	.34-.82	96.4
• Interpersonal Demands	7	21.4	26.2	27.5	0	.91	.53-.81	96.4
• Output Demands	7	25.7	26.2	15.6	0	.91	.60-.80	100
25-Item Work Limitations Questionnaire								
• Time Demands	5	36.6	35.3	13.9	.9	.89	.61-.82	100
• Physical Demands	6	32.2	33.3	20.9	1.7	.89	.63-.79	100
• Mental-Interpersonal Demands	9	28.8	25.5	14.8	0	.91	.57-.83	100
• Output Demands	5	26.0	26.0	16.5	0	.88	.53-.82	100

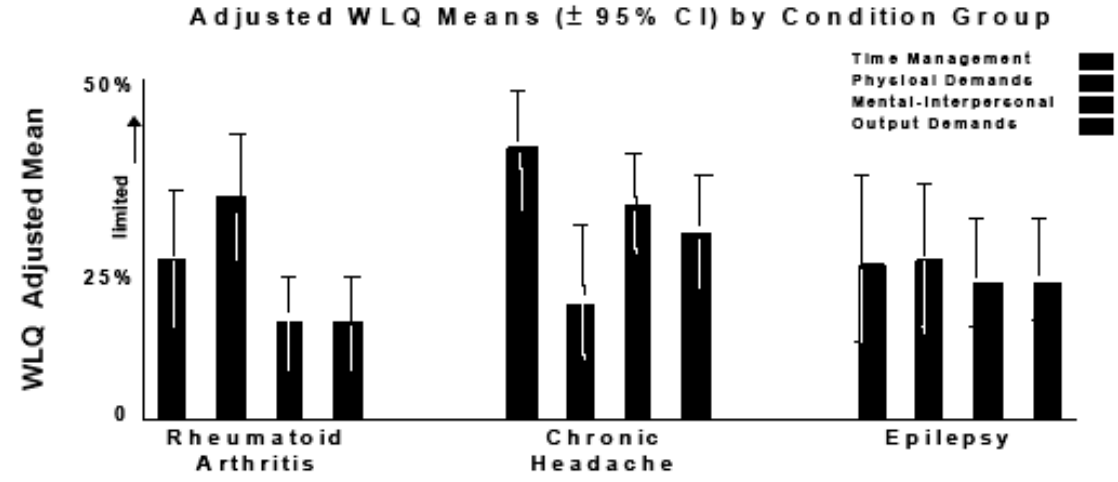
*p≤.01
n=121
*Minimum scale score (Least Limited) = 0. Maximum scale score (Most Limited) = 100
[a] Scaling success is the percent of tests out of all possible tests in which an item's correlation with its hypothesized scale is ≥ 2 SEs higher than its correlation with other scales.

Relative validity compares individual scales with regard to their performance on validity tests. Relative validity in our tests was based on a ratio of F-statistics generated by multiple regression. The dependent variable in each test was self-reported work productivity, and the independent (predictor) variable was a specific scale. Relative validity was the ratio of F for the scale being compared to the F of the best performing scale in the comparison. Relative validity ratios range from a score of 0 (minimum) to a score of 1 (the maximum, which represents the best performing scale in the comparison). In this comparison, we assessed the relative validity of the WLQ vs. the SF-36 role limitation scales, self-reported absences and self-reported job effectiveness for predicting self-reported work productivity loss. In separate regression models, the WLQ Output Demand scale had the best relative validity.

In a further validity test, we evaluated the WLQ's ability to detect differences between chronic condition groups. In the sample of 121 chronically ill patients, the WLQ detected several important differences; WLQ scale scores varied significantly by condition. Additionally, within each scale, the pattern of limitation was logically consistent with the characteristics of the different conditions. For example, headache syndrome involves sleep disturbance, fatigue, and extreme pain, which disrupt activities. The headache group was the more limited than either the rheumatoid arthritis group (p=0.02) or the epilepsy group (p□0.001) on the Time Demands scale. Headaches also involve visual and neurological disturbances, depressed affect, and irritability. Compared to either of the other two groups, the headache group was most limited on the Mental-Interpersonal Demands scale (in either comparison, p□0.01). On the Physical Demands scale, patients with rheumatoid arthritis were more limited than those with headache (p□0001) or epilepsy (p=0.03).



NOTE: F-values from regressions adjusted for age and gender (N=121)



Note: Adjusted for age and gender (n=121)

Bias

A sample of employed chronically ill workers and job-matched healthy coworkers (n=65) participated in a test of recall error. It compared retrospectively-reported WLQ scores to weekly diary reports of work limitations. Diaries were considered to be the gold standard of accuracy, requiring minimal recall.

Each subject completed the weekly diaries for four consecutive weeks. In addition, half of the sample completed a 2-week version of the WLQ at the end of study weeks 2 and 4. Half completed a

4-week version of the WLQ at the end of study week 4. Subjects were randomized to one or the other WLQ group.

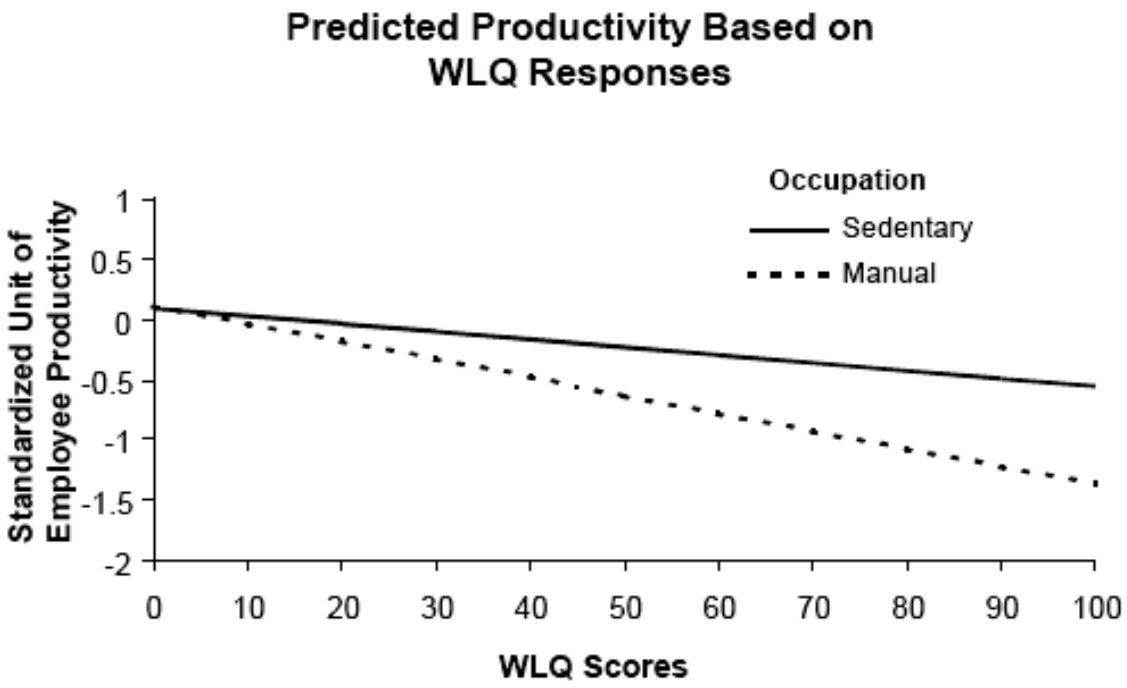
Because this test involved repeated administrations of work limitations questions, half of the WLQ item pool was included in the diaries (asking about work in the past week) and another half were embedded in the questionnaires. The content on the two forms was equivalent.

Multiple regression models tested the impact of memory on each WLQ scale. In separate models, each subject's data (questionnaire and diary data) was regressed on indicator variables measuring "subject" and a "method" variable. According to the intraclass correlation coefficient, recall error was not significant. Intraclass coefficients ranged from .76 to .90, thus, surpassing the recommended minimum .70 level.

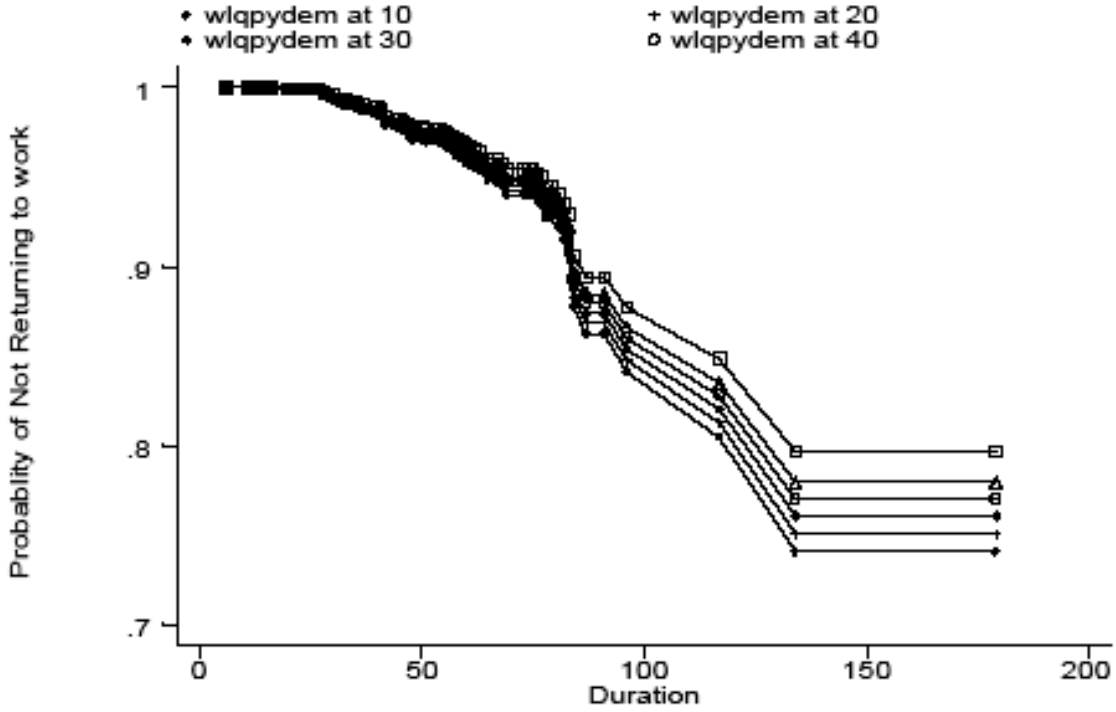
Criterion Validity

The relationship of WLQ scores to objectively-measured work productivity was tested in a sample of approximately 919 employees of a large New England firm that monitors employee productivity electronically. The WLQ was administered (on-site) during three months to non-absent employees assigned to eligible jobs (n= 2,185). Survey responses were compared to work productivity data obtained for the same period. The sample consisted of workers in sedentary and manual jobs. Sedentary Models. In 16 multiple regression models adjusted for correlated errors (4 scales x 4 productivity criteria), WLQ scores predicted work productivity in 9 models. The Output Demands scale predicted productivity, which is conceptually-related to productivity, in all 4 of its tests. Manual Models. In 4 adjusted models (4 scales x 1 productivity criterion), scores on the Time Management and Output Demands Scales explained a significant portion of the variation in productivity. WLQ Index. Results from the prior regressions confirmed that the Output Demands scale was a valid indicator of work productivity. To further explore the construct validity of the three other scales (Time Management, Physical and Mental/Interpersonal), we sought to identify the best combination of items for predicting productivity. In stepwise regressions, 8 items drawn from the scales were highly predictive of productivity in either sedentary or manual jobs.

The criterion validity of the WLQ was further tested in a study of short-term disability insurance claimants with low back pain. This sample included 167 claimants from firms throughout the nation, who had filed claims within four weeks of baseline. They were followed by survey for 12 weeks. In this study, the WLQ Physical Demands scale scores, obtained longitudinally, predicted duration of disability. The higher the WLQ Physical Demands scale score (WLQphydem), the greater the number of days spent on disability and not working (Duration).



Employee productivity in the sedentary occupation was number of calls/hour and in manual occupation it was merchandise units processed per hour. Each productivity criterion was standardized using its mean and standard deviation.



Considerations for Users.

The WLQ is available royalty-free for non-commercial applications.
Commercial applications are charged a user's fee. If you would like to obtain a copy of the WLQ, please contact us and ask for a user form. Complete and return the form and we will send you the WLQ. We ask that users consider sharing WLQ data they have collected so that we may continue to test the instrument and build a data base for users.

The user form can be obtained by contacting Dr. Debra Lerner's office at: 617-636-8636, The Health Institute, New England Medical Center Box 345, 750 Washington Street, Boston, MA 02111. Email: wlq@lifespan.org.

Work Limitations Questionnaire©

Sample Items

Work Limitations Questionnaire, © 1998, The Health Institute; Debra Lerner, Ph.D.; Benjamin Amick III, Ph.D.; and GlaxoWellcome, Inc. All Rights Reserved.

In the past 2 weeks, how much of the time did your physical health or emotional problems make it difficult for you to do the following?

	All of the Time (100%)	Most of the Time	Some of the Time (About 50%)	A Slight Bit of the Time	None of the Time (0%)	Does Not Apply to My Job
a. do your work without stopping to take breaks or rests	☐1	☐2	☐3	☐4	☐5	☐0
b. stick to a routine or schedule	☐1	☐2	☐3	☐4	☐5	☐0
c. keep your mind on your work	☐1	☐2	☐3	☐4	☐5	☐0
d. speak with people in person, in meetings or on the phone ……	☐1	☐2	☐3	☐4	☐5	☐0
e. handle the workload……	☐1	☐2	☐3	☐4	☐5	☐0

Note: Items a. and b. are from the Time Demands scale. Items c.and d. are from the Mental-Interpersonal Demands scale. Item e. is from the Output Demands scale.

In the past 2 weeks, how much of the time were you **ABLE TO DO** the following without difficulty caused by physical health or emotional problems?

(Mark one box on each line a. through f.)

	All of the Time (100%)	Most of the Time	Some of the Time (About 50%)	A Slight Bit of the Time	None of the Time (0%)	Does Not Apply to My Job
a. walk or move around different work locations (for example, go to meetings)	☐1	☐2	☐3	☐4	☐5	☐0
b. use hand-held tools or equipment (for example, a phone, pen, keyboard, computer mouse, drill, hairdryer, or sander)	☐1	☐2	☐3	☐4	☐5	☐0

Note: Items a. and b. are from the Physical Demands scale.

WORK PRODUCTIVITY AND ACTIVITY IMPAIRMENT QUESTIONNAIRE

The Work Productivity and Activity Impairment (WPAI) questionnaire measures work time missed and work and activity impairment because of a specified health problem during the past 7 days. The validity of the WPAI has been established in a number of diseases, e.g. allergies, dermatitis, gastroesophageal reflux disease, nocturia, irritable bowel syndrome, chronic obstructive pulmonary disease, and asthma. The WPAI has been proven to be a useful tool to measure the relative difference between treatment groups in clinical trials and in subjects with and without disease.

Abbreviated Name: WPAI
Author(s): Margaret Reilly
Purpose: To measure work and activity impairment during the past seven days
Population: Adult
Age Range : 16 and over
Type of Instrument: Work (and Daily Activity)
Mode of Administration:

Rater:	Self-/ Interviewer/ Telephone-administered
Time required:	2-3 minutes
Response Options:	Visual Analog Scale (VAS) / Write-in
Scoring:	Scores by dimension
Score Direction:	Lower scores show better QoL

Number of Items: WPAI GH: 9 / WPAI SHP: 6 / WPAI AS: 9
Original Language: English
Existing Translations :
WPAI-GH
French, German, Spanish, Russian
WPAI-SHP
Afrikaans, Arabic, Czech, Danish, Dutch, Finnish, French, German, Hebrew, Hungarian, Italian, Norwegian, Polish, Portuguese, Russian, Spanish, Swedish, Turkish
WPAI-AS
French, Japanese

Contact for information and permission to use:

Margaret Reilly, MA, MPH
Reilly Associates
425 E. 51st Street, 1B
New York, NY 10022
USA
Phone: +1 (646) 521-0072
Fax: +1 (212) 826-6560
E-mail: mreilly@reillyassociates.net

Dimensions covered by the questionnaire :

- Work (2 items)
- Daily activities (1 item)

Key References:

1. Reilly MC, Tanner A, Meltzer EO. Work, classroom and activity impairment instruments. Validation studies in allergic rhinitis. Clin Drug Invest 1996;11(5):278-288

2. Reilly MC, Zbrozek AS, Dukes EM. The Validity and Reproducibility of a Work Productivity and Activity Impairment Instrument. PharmacoEconomics 1993;4(5):353-365

The construct validity of a quantitative work productivity and activity impairment (WPAI) measure of health outcomes was tested for use in clinical trials, along with its reproducibility when administered by 2 different methods. 106 employed individuals affected by a health problem were randomised to receive either 2 self-administered questionnaires (self administration) or one self-administered questionnaire followed by a telephone interview (interviewer administration). Construct validity of the WPAI measures of time missed from work, impairment of work and regular activities due to overall health and symptoms, were assessed relative to measures of general health perceptions, role (physical), role (emotional), pain, symptom severity and global measures of work and interference with regular activity. Multivariate linear regression models were used to explain the variance in work productivity and regular activity by validation measures. Data generated by interviewer-administration of the WPAI had higher construct validity and fewer omissions than that obtained by self-administration of the instrument. All measures of work productivity and activity impairment were positively correlated with measures which had proven construct validity. These validation measures explained 54 to 64% of variance (p less than 0.0001) in productivity and activity impairment variables of the WPAI. Overall work productivity (health and symptom) was significantly related to general health perceptions and the global measures of interference with regular activity. The self-administered questionnaire had adequate reproducibility but less construct validity than interviewer administration. Both administration methods of the WPAI warrant further evaluation as a measure of morbidity.

Work Productivity and Activity Impairment Questionnaire:Allergy Specific (WPAI:AS)

The following questions ask about the effect of your allergies on your ability to work, attend classes, and perform regular daily activities. When you think about the past seven days, do not include today. Please check the line or fill in the blank as indicated.

1) Are you currently employed (working for pay)?

___NO ___YES

(If NO, check "NO" and skip to question 5.)

2) In general, how many hours per week do you usually work?

_____HOURS

3) During the past seven days, how many hours did you miss from work because of problems associated with your allergies? Include hours you missed because you were sick, times you went in late, left early, etc. because you were experiencing problems with your allergies. (Do not include time you missed to participate in this study.)

_____ HOURS

4) During the past seven days, how much did allergies affect your productivity while you were working? Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual. If allergies affected your work only a little, choose a low number. Choose a high number if allergies affected your work a great deal.

Allergies had no effect on my work _____ Allergies completely prevented me from working

0 1 2 3 4 5 6 7 8 9 10

CIRCLE A NUMBER

5) Do you currently attend classes in an academic setting (middle school, high school, college, graduate school, additional course work, etc.)?

___NO ___YES

(If NO, check "NO" and skip to question 9.)

6) In general, how many hours per week do you usually attend classes?

_____HOURS

7) During the past seven days, how many hours did you miss from class or school because of problems associated with your allergies? (Do not include time you missed to participate in this study.)

_____ HOURS

8) During the past seven days, how much did allergies affect your productivity while in school or attending classes in an academic setting? Think about days your attention span was limited, you had trouble with comprehension or days in which you could not take tests as effectively as usual. If allergies affected your productivity at school or in class only a little, choose a low number. Choose a high number if allergies affected your productivity a great deal.

Allergies had no effect on my class work

Allergies completely prevented me from doing my class work

0 1 2 3 4 5 6 7 8 9 10

CIRCLE A NUMBER

9) During the past seven days, how much did your allergies affect your ability to do your regular daily activities, other than work at a job or attend classes? By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like. If allergies affected your activities only a little, choose a low number. Choose a high number if allergies affected your activities a great deal.

Allergies had no effect on my daily activities

Alleries completely prevented me from doing my daily activities

0 1 2 3 4 5 6 7 8 9 10

CIRCLE A NUMBER

Work Productivity and Activity Impairment Questionnaire: Specific Health Problem V2.0 (WPAI:SHP)

The following questions ask about the effect of your PROBLEM on your ability to work and perform regular activities. *Please fill in the blanks or circle a number, as indicated.*

1. Are you currently employed (working for pay)? _____ NO ___ YES
If NO, check "NO" and skip to question 6.

The next questions are about the **past seven days**, not including today.

2. During the past seven days, how many hours did you miss from work because of problems associated with your PROBLEM? *Include hours you missed on sick days, times you went in late, left early, etc., because of your PROBLEM. Do not include time you missed to participate in this study.*

   _____ HOURS

3. During the past seven days, how many hours did you miss from work because of any other reason, such as vacation, holidays, time off to participate in this study?

   _____HOURS

4. During the past seven days, how many hours did you actually work?

   _____HOURS *(If "0", skip to question 6.)*

5. During the past seven days, how much did your PROBLEM affect your productivity while you were working?

Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual. If PROBLEM affected your work only a little, choose a low number. Choose a high number if PROBLEM affected your work a great deal.

Consider only how much PROBLEM affected productivity while you were working.

PROBLEM had no effect on my work	0	1	2	3	4	5	6	7	8	9	10	PROBLEM completely prevented me from working

CIRCLE A NUMBER

6. During the past seven days, how much did your PROBLEM affect your ability to do your regular daily activities, other than work at a job?

By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like. If health problems affected your activities only a little, choose a low number. Choose a high number if health problems affected your activities a great deal.

Consider only how much PROBLEM affected your ability to do your regular daily activities, other than work at a job.

PROBLEM had no effect on my daily activities	0	1	2	3	4	5	6	7	8	9	10	PROBLEM completely prevented me from doing my daily activities

CIRCLE A NUMBER

WPAI:SHP V2.0 (US English)

Work Productivity and Activity Impairment Questionnaire: General Health V2.0 (WPAI:GH)

The following questions ask about the effect of your health problems on your ability to work and perform regular activities. By health problems we mean any physical or emotional problem or symptom. *Please fill in the blanks or circle a number, as indicated.*

1. Are you currently employed (working for pay)? ____ NO ____ YES
   If NO, check "NO" and skip to question 6.

The next questions are about the **past seven days**, not including today.

2. During the past seven days, how many hours did you miss from work because of your health problems? *Include hours you missed on sick days, times you went in late, left early, etc., because of your health problems. Do not include time you missed to participate in this study.*

   _____HOURS

3. During the past seven days, how many hours did you miss from work because of any other reason, such as vacation, holidays, time off to participate in this study?

   _____HOURS

4. During the past seven days, how many hours did you actually work?

   _____HOURS *(If "0", skip to question 6.)*

5. During the past seven days, how much did your health problems affect your productivity while you were working?

Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual. If health problems affected your work only a little, choose a low number. Choose a high number if health problems affected your work a great deal.

Consider only how much health problems affected productivity while you were working.

Health problems had no effect on my work	0	1	2	3	4	5	6	7	8	9	10	Health problems completely prevented me from working

CIRCLE A NUMBER

6. During the past seven days, how much did your health problems affect your ability to do your regular daily activities, other than work at a job?

By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like. If health problems affected your activities only a little, choose a low number. Choose a high number if health problems affected your activities a great deal.

Consider only how much health problems affected your ability to do your regular daily activities, other than work at a job.

Health problems had no effect on my daily activities	0	1	2	3	4	5	6	7	8	9	10	Health problems completely prevented me from doing my daily activities

CIRCLE A NUMBER

The following questions ask about the effect of your IBS symptoms e.g., abdominal discomfort, abdominal pain, bloating, constipation, and diarrhea, on your ability to work and perform regular daily activities.

Please fill in the blanks or circle a number, as indicated.

1) Are you currently employed (working for pay)? ____NO ___YES

If NO, check "NO" and skip to question 6

The next questions are about the **past seven days**, not including today.

2) During the past seven days, how many hours did you miss from work because of problems associated with your IBS symptoms?

Include hours you missed on sick days, times you went in late, left early, etc. because of IBS symptoms. Do not include time you missed to participate in this study.

_____HOURS

3) During the past seven days, how many hours did you miss from work because of any other reason, such as vacation, holidays, time off to participate in this study?

_____HOURS

4) During the past seven days, how many hours did you actually work?

_____HOURS *(If "0", skip to question 6)*

5) During the past seven days, how much did **IBS symptoms** affect your productivity <u>while you were working?</u>

Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual. If IBS symptoms affected your work only a little, choose a low number. Choose a high number if IBS symptoms affected your work a great deal.

Consider only how much <u>IBS symptoms</u> affected productivity <u>while you were working</u>.

IBS symptoms had no effect on my work — 0 1 2 3 4 5 6 7 8 9 10 — IBS symptoms completely prevented me from working

Circle a number

6) During the past seven days, how much did IBS symptoms affect your ability to do your regular daily activities, other than work at a job?

By regular activities, we mean the usual activities you do, such as work around the house, shopping, child care, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like. If IBS symptoms affected your activities only a little, choose a low number. Choose a high number if IBS symptoms affected your activities a great deal.

Consider only how much <u>IBS symptoms</u> affected your ability to do your regular daily activities, other than work at a job.

IBS symptoms had no effect on my daily activities — 0 1 2 3 4 5 6 7 8 9 10 — IBS symptoms completely prevented me from doing my daily activities

Circle a number

7) Do you currently attend classes in an academic setting (middle school, high school, college, graduate school, additional course work, etc.)? _____NO _____YES

(If NO, check "NO" and STOP.)

8) During the past seven days, how many hours did you miss from class or school because of problems associated with your IBS symptoms? Do not include time you missed to participate in this study.

_____ HOURS

9) During the past seven days, how many hours did you actually attend class or school?

_____ HOURS *(If "0", enter "0" and STOP)*

10) During the past seven days, how much did your IBS symptoms affect your productivity while in school or attending classes in an academic setting?

Think about days your attention span was limited, you had trouble with comprehension or days in which you could not take tests as effectively as usual. If IBS symptoms affected your productivity at school or in class only a little, choose a low number. Choose a high number if IBS symptoms affected your productivity at school or in class a great deal.

Consider only how much IBS symptoms affected productivity while in school or attending classes.

IBS symptoms had no effect on my class work	0	1	2	3	4	5	6	7	8	9	10	IBS symptoms completely prevented me from doing my class work

Work Productivity and Activity Impairment Questionnaire: Electronic Data Collection – Sample Screenshots

Screen No.		Screen No.	
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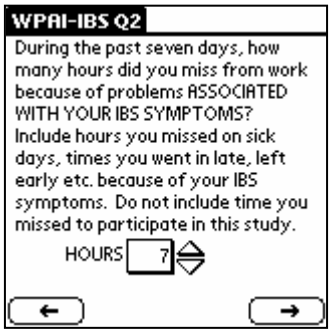
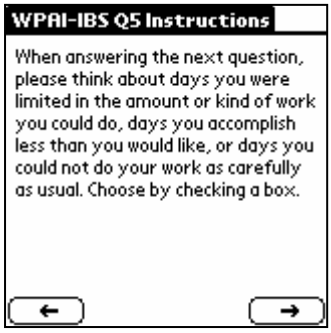
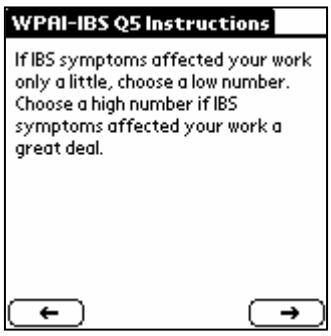
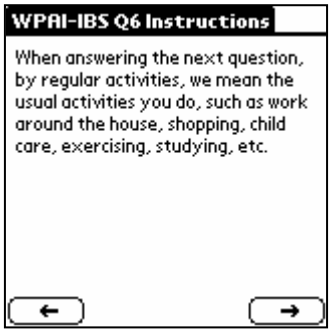
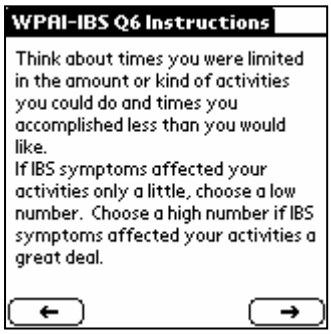
WP 1.2		WP 1.3	
WP 1.4		WP 1.5	
WP 1.6		WP 1.7	

Screen No.		Screen No.	Note: “accomplished” is correct
WP 1.75		WP 1.8	
WP 1.9		WP 1.10	
WP 1.11			

ZUNG SELF-RATING ANXIETY SCALE

The Zung Self-Rating Depression Scale is a 20-item self-report questionnaire that is widely used as a screening tool, covering affective, psychological and somatic symptoms associated with depression. The questionnaire takes about 10 minutes to complete, and items are framed in terms of positive and negative statements. It can be effectively used in a variety of settings, including primary care, psychiatric, drug trials and various research situations. Each item is scored on a Likert scale ranging from 1 to 4. A total score is derived by summing the individual item scores, and ranges from 20 to 80. Most people with depression score between 50 and 69, while a score of 70 and above indicates severe depression. The scores provide indicative ranges for depression severity that can be useful for clinical and research purposes, but the Zung scale cannot take the place of a comprehensive clinical interview for confirming a diagnosis of depression. The Zung scale also provides a simple tool for monitoring changes in depression severity over time in research studies.

Abbreviated Name: Zung SAS
Author(s): William WK Zung
Purpose: To quantify the severity of current depression in patients of all ages with a primary diagnosis of depressive disorder
Population: All
Type of Instrument: Quality of life / Symptom/ Functioning
Mode of Administration:

Rater:	Self-administered
Time required:	10 minutes
Response Options:	Likert scale
Scoring:	Global score
	Scores by dimension
Score Direction:	Lower scores show better QoL

Number of Items: 20
Original Language: English
Existing Translations: Dutch, Finnish, French, German, Italian, Japanese, Norwegian, Russian, Spanish, Yoruba

Contact for information and permission to use:

Psychosomatics
American Psychiatric Press, Inc.
1400 K Street
N.W. Washington, DC 20005
Phone: +1 (202) 682-6336

Dimensions covered by the questionnaire :

- Affective symptoms
- Somatic symptoms

Key References:

1. Zung WWK. A Rating Instrument for Anxiety Disorders. Psychosomatics 1971;12(6):371-379
2. Zung WWK, Magruder-Habib K, Velez R et al. The comorbidity of anxiety in general medical patients: a longitudinal study. Journal of Clinical Psychiatry 1990;51(S6):S77-S80
3. Lindsay WR, Michie AM. Adaptation of the Zung self-rating anxiety scale for people with a mental handicap. J Ment Defic Res. 1988 Dec;32 (Pt 6):485-90.
4. Zung WWK. Effect of clorazepate on depressed mood in anxious patients. Journal of Clinical Psychiatry 1987;48:13-14
5. Zung WWK. Prevalence of clinically significant anxiety in a family practice setting. Am J Psychiatry 1986;143(11):1471-1472
6. Jegede RO. Psychometric characteristics of Yoruba versions of Zung's self-rating depression scale and self-rating anxiety scale. Afr J Med Med Sci. 1979 Sep-Dec;8(3-4):133-7.
7. Zung WWK. The measurement of affects: Depression and anxiety. Pharmacopsychiatry 1974;7:170-188

NAME _____ DATE _____

Zung Anxiety Self-Assessment Scale

	None or a little of the time	Some of the time	Good part of the time	Most or all of the time
1. I feel more nervous and anxious than usual	1	2	3	4
2. I feel afraid for no reason at all	1	2	3	4
3. I get upset easily or feel panicky	1	2	3	4
4. I feel like I'm falling apart and going to pieces	1	2	3	4
5. I feel that everything is all right and nothing bad will happen	4	3	2	1
6. My arms and legs shake and tremble	1	2	3	4
7. I am bothered by headaches, neck and back pains	1	2	3	4
8. I feel weak and get tired easily	1	2	3	4
9. I feel calm and and can sit still easily	4	3	2	1
10. I can feel my heart beating fast	1	2	3	4
11. I am bothered by dizzy spells	1	2	3	4
12. I have fainting spells or feel faint	1	2	3	4
13. I can breath in and out easily	4	3	2	1
14. I get feelings of numbness and tingling in my fingers and toes	1	2	3	4
15. I am bothered by stomachaches or indigestion	1	2	3	4
16. I have to empty my bladder often	1	2	3	4
17. My hands are usually dry and warm	4	3	2	1
18. My face gets hot and blushes	1	2	3	4
19. I fall asleep easily and get a good night's rest	4	3	2	1
20. I have nightmares	1	2	3	4

Converting Raw Score Total to Anxiety Index

RAW SCORE	ANXIETY INDEX	RAW SCORE	ANXIETY INDEX	RAW SCORE	ANXIETY INDEX
20	25	40	50	60	75
21	26	41	51	61	76
22	28	42	53	62	78
23	29	43	54	63	79
24	30	44	55	64	80
25	31	45	56	65	81
26	33	46	58	66	83
27	34	47	59	67	84
28	35	48	60	68	85
29	36	49	61	69	86
30	38	50	63	70	88
31	39	51	64	71	89
32	40	52	65	72	90
33	41	53	66	73	91
34	43	54	68	74	92
35	44	55	69	75	94
36	45	56	70	76	95
37	46	57	71	77	96
38	48	58	73	78	98
39	49	59	74	79	99
				80	100

Raw Score Total ☐ Anxiety Index ☐

Interpreting the Anxiety Index

Anxiety Index	Clinical Interpretation
Below 45	Within normal range
45 – 59	Minimal to moderate anxiety
60 – 74	Marked to severe anxiety
75 and over	Most extreme anxiety

- **Check that all statements have been answered**
- **Scoring values are printed next to the response**
- **Add up the Raw Total Score**
- **Convert the Raw Total to the Anxiety Index**

Instruction for use: (Zung Anxiety Assessment Tool)

1. The same caregiver should administer this test each time.
2. Choose a quiet place, preferably the same location each time the test is administered.
3. The administration of this test should not be immediately after some mental trauma or unsteady period.
4. Speak in a soft, pleasant tone.
5. Answer all questions by placing a check in the box to the left of the number under the appropriate answer.
6. Add the Raw Score values (numbers to the right of the check) for all questions and record the total in the "RAW SCORE TOTAL" box.
7. Compare the raw score to the anxiety index on the conversion chart and record the corresponding anxiety index in the "ANXIETY INDEX" box.
8. Compare the anxiety index with the clinical interpretation chart.