MEDICAL AND CARE COMPUNETICS 5

# Studies in Health Technology and Informatics

This book series was started in 1990 to promote research conducted under the auspices of the EC programmes' Advanced Informatics in Medicine (AIM) and Biomedical and Health Research (BHR) bioengineering branch. A driving aspect of international health informatics is that telecommunication technology, rehabilitative technology, intelligent home technology and many other components are moving together and form one integrated world of information and communication media. The complete series has been accepted in Medline. Volumes from 2005 onwards are available online.



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# Medical and Care Compunetics 5

Edited by

Lodewijk Bos

*President ICMCC*

Bernd Blobel

*eHealth Competence Center,*
*University of Regensburg Medical Center, Germany*

Andy Marsh

*VMW Solutions*

and

Denis Carroll

*University of Westminster*

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4502 Rachael Manor Drive
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USA
fax: +1 703 323 3668
e-mail: iosbooks@iospress.com



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*Medical and Care Compunetics 5*
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# Preface

This book accompanies the fifth annual ICMCC Event.

ICMCC is becoming one of the leading information platforms for medical and care ICT. This is reflected in this year's ICMCC event programme which includes even more examples of compunetics, the social, societal and ethical aspects of medical and care ICT. With a growing number of papers, authors come from almost all continents.

The 2008 ICMCC Event deals with the following subjects:

- National and Regional Projects;
- Aspects of Electronic Health Records;
- European Projects, organised by Artur Krukowski and Andy Marsh;
- Knowledge Management, organised by Rajeev Bali and Nilmini Wickramasinghe;
- Platforms;
- Behavioral compunetics, organised by Stephen Benton;
- Empowerment;
- Personal Health Paradigm Challenging Citizens and Patients, organised by Prof. Dr. Bernd Blobel from the eHealth Competence Center (University of Regensburg Medical Center, Germany) jointly with the European Federation for Medical Informatics (EFMI) Working Groups "Electronic Health Records (EHR)" and "Security, Safety and Ethics (SSE)".

I would like to thank all the members of the scientific board for their work in preparing this event and especially Denis Carroll, Andy Marsh and Bernd Blobel.

On behalf of the ICMCC Foundation board I wish to thank the University of Westminster Business School for hosting this conference.

I also would like to thank the UK Department for Business, Enterprise and Regulatory Reform (BERR), the British Computer Society (the HIISCG and the Sociotechnical Group), the IFMBE and the BIOPoM for supporting our event.

Finally I would like to thank all the authors who have contributed to making the fifth ICMCC Event into an interesting and challenging conference.

Lodewijk Bos
Event chair

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# "The impatient patient"

Lodewijk Bos[a,1], Denis Carroll[b], Andy Marsh[b]
[a] *ICMCC president*
[b] *ICMCC Vice-President*

Abstract. Modern Healthcare Systems that have embraced ICT and Internet technologies (referred to as Health 1.0) are evolving towards self management but from a clinical knowledge perspective. In contrast, from a user experience perspective, and using the latest web 2.0 technologies, the developing healthcare social networking communities (referred to as Health 2.0) are evolving towards becoming online medical portals.
The growing Grand Challenge for healthcare is therefore: how will health care services (Health 1.0) work together with user-generated health care (Health 2.0) in a consumer market place delivering self management services for a healthier lifestyle and medical compliance. What is foreseen is that the self care information tool of the future will be a combination between the patient's observation record and the Internet, with the doctor and the patient positioned together at the intersection but not having to pay attention to the technology.
This article deals with various aspects related to this Grand Challenge like the paradigm shift towards a needs-led and consumer-oriented healthcare, the role, supply and quality of information and the changing doctor-patient relationship.

## 1. Introduction

In 2002, the cumulative health spending of 24 Organisation for Economic Co-operation and Development (OECD) countries was $2.7 trillion. Moreover, Pricewaterhouse-Coopers [1] estimates that health spending for OECD countries will more than triple to $10 trillion by 2020. Healthcare organizations and governments around the world are urgently seeking solutions to temper costs while balancing the need to provide access to safe and high quality care. Yet, conventional approaches are failing, even in the most advanced nations of the world – throughout Europe, Asia, the Middle East, Australia, Canada and the United States.

According to the Royal Society report published on 8/12/06, low cost technology is the key to improve healthcare. Everyday technologies such as mobile phones and personal computers should not be overlooked in favour of large computer projects, such as the National Programme for IT (Connecting for Health), to improve the UK healthcare system. Furthermore the cost of telecommunications and computing power has dropped so dramatically that the potential finally exists to unite healthcare providers with patients and purchasers in a virtual seamless system with negligible costs. [3]

Preventive care, disease and lifestyle management programmes have much potential to enhance health status, reduce costs and introduce new cost sharing models but require support and integration across all the stakeholders for their benefits to be realised. A vision strategy needs to focus on investing multi-disciplinary research

[1] ÍCMCC, Stationsstraat 38, NL-3511 EG Utrecht, lobos@icmcc.org

expertise and incorporating small-scale innovative technologies into an open platform for strategically important leading-edge developments across the wider spectrum of health, housing, social care and community safety by combing Information and Communication Technologies (ICTs) with that of care process optimisation and coordination for cost effective mass market self care management.

ICT has the potential to transform radically the delivery of healthcare to include prevention, well-being and disease avoidance and to address future health challenges. Whether they actually do so will depend on sufficiently accounting for the users' needs and the provision of adequate support and training after their introduction. The introduction of digital information systems offers the potential to deliver new interactive services to people at the point of need, in their own homes [2].Tele-everything through television sets and other terminals will change the way patients are treated, operated on, monitored and counselled [3]. It is possible to store information and for users or carers to access it at convenient times. Urgent information triggered by alarms, changes in vital signs, or health status monitors can be transmitted and acted upon immediately. However, the best benefit to cost ratio will result from the deployment of the most appropriate solution for individual needs. Rather than being **'technology-driven'**, all solutions must be **'needs-led'** and identify the most appropriate technology to fit. The single most important factor in realising the potential of ICTs for self care is the people who use them, both carers and patients. As seen from VoIP (Voice over Internet Protocol) the end users, the "consumers", will drive the adoption of new technologies and services in the mass retail market.

Since the patient/consumer is the primary source of information to be accepted, support systems for decision making must be integrated into everyday life. They must present the right information, in the right format, at the right time, without requiring special effort. In other words, they cannot impeach on day-to-day realities of living. They cannot require users to learn to use a series of disconnected computer systems and must not be at odds with doctors' concept of the medical record or sense of autonomy in decision-making.

The Grand Challenge is therefore: how will health care services (Health 1.0) work together with user-generated health care (Health 2.0) in a consumer market place delivering self management services for a healthier lifestyle and medical compliance. What is foreseen is that the self care information tool of the future will be a combination between the patient's observation record and the Internet, with the doctor and the patient positioned together at the intersection but not having to pay attention to the technology.

The next three sections present an example of health 1.0, an overview of health 2.0 and whether the Internet is providing information or mis-information. Section 5 addresses the issues that consumerism will have on the conventional healthcare model and subsequent patient's expectations. Section 6 addresses the resulting doctor-patient relationship and section 7 presents the conclusions.

## 2. Health 1.0 and the need for change

The locus of power in health care is shifting: instead of the doctor acting as sole manager of patient care, a consumerist model has emerged in which patients and their doctors are partners in managing their care. A number of studies focus on whether the Internet can actually empower patients and enrich the patient-doctor relationship

[38,43]. On the other hand, there are many organisational and behavioral barriers to patients being involved in managing their healthcare [42] so a study should also address how the Internet model would affect these.

Public use of the Internet as a health care tool has grown dramatically in the past few years, and this trend is expected to continue. Obtaining information from the Web is often the basis for making health decisions and is thus an influential force. Of persons surveyed in 2000 by the Pew Internet & American Life Project, 41% said that the Internet affected their decisions about going to a doctor, treating an illness, or questioning their doctor. To obtain such information in the most optimal and safe way, Electronic Health Records (EHRs) should be structured in such a way that they can serve as the basis. [8]

"Medical knowledge is becoming increasingly specialised and there is an inevitable 'competence gap' between medical doctors and their patients. Through online information sources, citizens can to some extent bridge this 'competence gap' by informing themselves about disease prevention and healthy lifestyles, various health problems and treatment options. This can have an empowering effect and allow patients to exercise a certain degree of choice." [7]

People are demanding the same easy access to advanced health care technology as is currently available to them when they do their banking or plan a vacation. The era of the "impatient patient" has arrived. Patients demand immediate, convenient access to a high level of personalised health care: they want it their way, and they want it now.

During the last years, a significant amount of money has been invested to evaluate monitoring via the Internet to home users worldwide. These types of studies, which will serve as important test cases for the possibility of e-technology to improve health outcomes have to be continued and extended during the following years by including long-term follow up and solid clinical measures. Furthermore, more research is needed utilizing larger samples over longer periods, controlled and randomised, in tandem with significant outcomes to support policy changes and buy-in efforts for implementation.

Several monitoring devices using the Internet have been developed to help patients manage their medical conditions at home. Research is needed regarding health outcomes, cost effectiveness, as well as the long-term acceptance of these devices by patients.

Breast cancer patients in an online education and support group had increased confidence in their doctors, as well as increased competence to deal with relevant, disease-related information. These patients were also more comfortable seeking information during a doctor office visit and were more comfortable participating in their own care. This study alone is minimal evidence to support changes in the patient-doctor relationship and more research is needed. [41]

According to an online poll, it was found that patients who use the Internet to look for health information are more likely to ask more specific and informed questions of their doctors and to comply with prescribed treatment plans. This was a survey and not a formal study. Further research is necessary to understand what effect the Internet age has on the patient-doctor relationship. For example, are patients more compliant with prescribed therapy because they discussed it more with their doctor or because they read it on the Web? [40]

The Internet offers an important opportunity for patients to become actively engaged in their own care. [8] During the pre-Internet era, medical information was published in medical textbooks and journals only, whereas patients can now gain access to citations of more than 12 million medical articles online. Indeed, many

patients are now helping to inform their doctors on the latest research and treatments. Doctors Gerber and Eiser postulate that the Internet age offers opportunities to improve the patient-doctor relationship by sharing the burden of responsibility for knowledge. They also underline the necessity for research to identify the effects on the patient-doctor relationship, as well as the effects on patient and doctor satisfaction and on health outcomes especially since healthguides[2] provides a common set of clinically based guidelines. [36]

New to the world of care and cure is the concept of the Expert Patient. The NHS website defines it as follows: "Expert patients are people living with a long-term health condition, who are able to take more control over their health by understanding and managing their conditions, leading to an improved quality of life." [9] In his 2001 report, the UK chief medical officer Liam Donaldson, characterised them as people: "who enjoy good quality of life despite chronic disease; who have the confidence, skills, input and knowledge to play a central role in the management of life with chronic disease, and to minimise its impact on their day-to-day living." [10]

However, these definitions focus on people with chronic diseases. Any patient, whatever their condition, should be able to become an expert patient. The way to achieve this is through information. [11] Through the proper information the citizen will be able to take more responsibility in the way they live and, once they become a patient, in the way they will be treated. "The greatest benefit could come in the future if patients could take on more responsibility for their bodies and minds… Doctors then may come to acknowledge… that doctoring is something of a joint venture between patient and healer, in which the doctor serves as a guide."[12].

Whether the medical community looks forward to the advance of this paradigm shift, is uncertain. "The suspicion is that for many doctors, the expert patient of the imagination is the one clutching a sheaf of printouts from the internet, demanding a particular treatment that is unproved, manifestly unsuitable, astronomically expensive, or all three. Or, possibly worst of all, a treatment the doctor has never heard of, let alone personally prescribed."[13]

## 3. User-generated healthcare (Health 2.0)

Five years ago, online content generated by individual web surfers was seen as something done by the technically gifted. Keeping a 'blog' was akin to being a computer coder. In recent years, there has been an incredible boom in user-generated content. Wikipedia is an online encyclopaedia written by thousands of global users. Even more recently, 'social networking' portals have become some of the most popular web sites, offering users a chance to connect to peers worldwide. For example, UK participation in social networking was revealed to be the highest in Europe, with 24.9 million unique visitors – 78% of the total adult online population – now belong to the UK's social networking community. [39]

The boom in "user-generated content" is also addressing healthcare. Millions are now logging on to contribute information about topics stretching from aviation flu

[2] The Map of Medicine represents the state of the art in health 1.0. The map, intended for clinical use, is a web-based visual representation of evidence-based patient care journeys covering 28 medical specialties and 387 pathways. A patient version of the map, called Healthguides, is now being created by more than 500 doctors and nurses to give patients the same in-depth clinical information as used in the NHS, in easy to follow charts. http://www.mapofmedicine.com/

pandemics to the extraction of wisdom teeth. The "Economist" terms this *user-generated health care* or *Health 2.0*. (see also: [14]) The explosion of user-generated content in health care is in part the result of a broader internet trend; more and more people have broadband access and the tools for creating content and getting easier to use. But there are other drivers. Those with multiple chronic conditions, such as diabetes and depression, or lesser known diseases such as chronic fatigue syndrome, are anxious to get tips from others in similar situations.

Online support groups exist for almost every disease and condition, and discussion topics within each disease category are limitless. For example, diabetic patients who enjoy scuba diving can learn from fellow diabetic scuba divers how to cope with diabetes 50 feet (15.2 meters) below the water's surface. But just as important as the information exchanged in these e-discussions is the emotional support they provide. For each e-patient seeking a listening "ear," dozens of other patients offer encouragement. In turn, these words of solace are read by hundreds (and sometimes thousands) of other patients who read Internet message boards. This support may be recorded for future reference of patients, doctors, or health care planners.[3]

## 4. Internet and information or misinformation

Miss-use, misinformation and the sheer volume of health information are issues of concern. However, consumers concur that the upside outweighs the risk. Nearly one-third of the 100 Million Americans who looked for health information online say that they have been significantly helped. In contrast only 3% reported that online advice had caused serious harm. Furthermore, user-generated health content is in general accurate. A panel of neurology specialists judged that only 6% of content posted to the epilepsy support group of braintalk was factually wrong. In general with enough people online, misinformation is often quickly corrected

"In the early nineties, under the aegis of the United States National Information Infrastructure, the Internet facilitated the creation of an "information-for-all" environment. Despite the unstructured nature of its existence, the Internet has seen an unprecedented global growth in its role as a promoter of information solutions to the citizens of the world" wrote ICMCC's co-founder Swamy Laxminarayan. [15]

Nowadays, information is available in abundance. Through publications, research communities, international projects, more and more people have access to information. Especially in the health area there is a need for it. "The number of people who have used the Internet to search for health-related information has increased markedly, (from 53% in 2005 to 71% currently). This brings the number of all U.S. adults who have ever searched for health information online to 160 million, from 136 million in 2006 and 117 million in 2005 — a 37 percent increase over two years. […] Two thirds (66%) of adults online say that they have looked for information about health topics often (26%) or sometimes (40%), an increase of five percentage points from 2006 (61%)." [16]

However, there are risks involved. "In a large number of Web sites currently offering health information we cannot find credible and enforceable protection of

[3] Some examples:
Patient opinion, http://www.patientopinion.org.uk/
I'm too young for this, http://imtooyoungforthis.org/

citizens from potential harm" [17] "Most studies (55 [70%]) concluded that quality is a problem on the Internet" [18]

People have a broad range of information preferences that may differ at different times and for different reasons. They may want more information than prescribers want to give—for example, about the possible side effects of a drug. They may place different interpretations on information about likely risks, and they may question the benefits of taking a drug when they are not greatly concerned by the medical "problem" that the treatment is meant to solve. They may well rate the practicalities of how to take a drug higher than the details of the inert components of the pills or the drug manufacturer's address. [19]

The internet has given an enormous boost to the discussion about freedom of access to information and knowledge. Access to information and knowledge must be free, especially information originating from public and publicly controlled bodies. True however is that quite a large amount of the information available on the internet is non-information and non-knowledge. In such specific areas as health and care we will have to start the discussion about how to validate information such that even those who do not have the capacities to separate the wheat from the chaff can trust the information they want to access. "In a large number of Web sites currently offering health information we cannot find credible and enforceable protection of citizens from potential harm" [20]

Due to the way information is organised we will differentiate between scientific and non-scientific information as described in the following sections.

### *4.1. Scientific information*

With the growing need to be informed, the citizen demonstrates more interest in scientifically based information. "In 2005, the criteria perceived as the most important indicators of quality and usefulness for health Web sites among non-professional and professional groups of users: (1) availability of information, (2) ease of finding information/navigation, (3) trustworthiness/credibility and (4) accuracy of information. Both non-professional and professional users, in Europe and the USA, favor academic/university sites (89.4%, n=1403) and sites sponsored by medical journals (88.9%, n=1394), closely followed by government agencies (86.1%, n=1395). We have also observed that a significant number of Web users, about 25% of a sample of 1,386 persons from all over the world, lack confidence in sites sponsored by pharmaceutical manufacturers and commercial, mainstream media organizations." [2,6]

"Medical knowledge is becoming increasingly specialised and there is an inevitable 'competence gap' between medical doctors and their patients. Through online information sources, citizens can to some extent bridge this 'competence gap' by informing themselves about disease prevention and healthy lifestyles, various health problems and treatment options. This can have an empowering effect and allow patients to exercise a certain degree of choice." [7]

Although the number of so-called open source journals and publications increases, many of the scientific publications are available only at relatively high subscription costs. However, there are a number of international initiatives to make these publications freely available.

- The *HINARI* [22] program, set up by WHO together with major publishers, enables developing countries to gain access to one of the world's largest collections of biomedical and health literature.

- *INASP Health* [23] works towards a future where all healthcare providers, researchers, educators and policymakers can access and contribute information and knowledge for better health and healthcare worldwide.
- *HTAi* [ 24] (Health Technology Assessment International) focuses uniquely on health technology assessment (HTA) and provides the key forum for all those from the worlds of health care, academia and business interested in the science, development and application of HTA.
- The *EAHIL* [25] (European Association for Health Information and Libraries) wants to improve library services to the health professions by cooperation and shared experience across national boundaries.

These organisations aim at professionals only, either worldwide or in developing countries. We think that these facilities should also be available to patients. The expert patient is a relatively new phenomenon that will become more and more common in the next couple of years. By creating this information portal, we will help them to become an expert patient based on coordinated access. (see also 4.2)

### *4.2. Non-scientific information*

General health information sites should be on a national level, as much of the information about diseases, treatments and quality and location has a strong national orientation. We should aim at making the information on these national sites also accessible to people from other countries. Especially in Europe this is necessary, due to on the one hand holiday traveling, on the other hand the European rule, that patients are free to seek medical assistance outside their own country.

Fundamentally these sites are not only about diseases but about health, informing not only patients but also citizens in general. Well being is becoming increasingly important and we should supply citizens with information on what is nowadays called complimentary and alternative medicine, offering alternatives to our own, reparative medical tradition.

The amount and complexity of information must be tailored to the perceived needs of a patient. Access to further information should be facilitated, and patients helped in interpreting the data. The internet has greatly expanded the availability of information, but this is often disjointed, incomplete, apparently conflicting, and not aimed at a general audience. The use of information from the web varies considerably across socioeconomic groups. Therefore, to improve access to information, it should in future be provided in a variety of formats—spoken, written, and pictorial. [26]

Another essential aspect is the independence of such portals/platforms. It is with full agreement that we quote here James Kennedy, a British GP: "I would like to see the establishment of a specialised and rigorous "information source" independent of both the health service and pharmaceutical industry. It would act as an quality controller for information from a variety of sources—research communities in universities, specialist professional bodies, and pharmaceutical companies. Such a trusted resource could monitor, assess, and interpret the research evidence in each clinical area and become an authoritative, but not exclusive, information provider for clinicians and the public. It could also be invited to develop and test methods for information dissemination." [26] How accurate Kennedy's observation is, follows from a study by Joergensen et al.: "the information presented to women on websites by professional advocacy groups and governmental organisations was selective and biased and failed to mention major harms. Websites from consumer groups were more

balanced and comprehensive than sites by professional advocacy groups and governmental organizations."[27]

### *4.3. Literacy*

To be able to access and understand the available information, a certain level of eHealth literacy is desirable if not mandatory. "eHealth literacy is influenced by a person's presenting health issue, educational background, health status at the time of the eHealth encounter, motivation for seeking the information, and the technologies used. Like other literacies, eHealth literacy is not static; rather, it is a process-oriented skill that evolves over time as new technologies are introduced and the personal, social, and environmental contexts change. Like other literacy types, eHealth literacy is a discursive practice that endeavors to uncover the ways in which meaning is produced and inherently organises ways of thinking and acting. It aims to empower individuals and enable them to fully participate in health decisions informed by eHealth resources." [32] Norman et al. define 6 components of the eHealth literacy model: traditional, information, media, health, computer and scientific literacy [32].

## 5. Healthcare as a consumer commodity

The availability of easily accessible information will be at the heart of any consumer driven healthcare information retrieval system. Consumers will also assume greater responsibility for choosing their health benefits and providers. Online Health plan products will guide decision making based on healthcare needs and budgets to allow employers and/or employees to choose from a variety of benefits and identify the best alternative for each situation. Recent research shows that the use of telecare has additional social benefits [28]. Consumers will have greater financial responsibility in both purchases and care. Consumers will become active participants and control care decisions and help manage their health. As the number of people with chronic conditions grows, health plans will need to step up even more as the primary sponsors of voluntary disease and health management programmes. Consumers will expect medical devices to be familiar, friendly, interoperable and have easy to use processes for data capture. Consumers will require easy to use appropriate knowledge management tools to assess the generated knowledge and integrating this knowledge to the knowledge gained from the patient's clinical history.

Since the evolving healthcare model is addressing the consumer market on a mass scale a number of underlying issues have to be taken into consideration including organisational (remote monitoring implications), cost-benefit (are indirect costs included), elderly (are the services useable), teenager (are they catered for), carer (what is the learning curve), durability (robustness, maintainability), usability (do the solutions work in real life), user experience (also risk groups) [37]. In addition, networks of medical doctors enabling easy communication amongst themselves about problems with patients, questions about diagnostics or treatments, in short, exchanging information and knowledge will become of immense importance. Most of this communication can be done almost real time due to the internet. Within the networks doctors can share detailed information in the form of email attachments, be it laboratory results, images or their own observations. [30]

Contrary to previous times, knowledge has become more and more specialised. Therefore, cooperation networks have become a necessity. A doctor depends on X-ray technology or MRI scans to make a diagnosis, he needs cooperation with surgeons or physiotherapists to enable improvement of his patient's condition. Once again, contact between members of those cooperation networks can become instantaneous, independent of location. Via broadband facilities, colleagues can be visually contacted for advice and/or assistance.

With the most recent telecommunication developments, they can invite colleagues to observe operations real time or even take part in them, no matter what the distance is between them. They can build communities that hardly suffer from the ancient communication problems, being distance in time and place.

Pagliari et al [31, table 1] give an overview of the "Professional Clinical Informatics" issues that dominate e-health:

- Decision aids for practitioners (e.g., prompts, reminders, care pathways, guidelines)
- Clinical management tools (e.g., electronic health records [EHRs/EPRs], audit tools)
- Educational aids (guidelines, medical teaching)
- Electronic clinical communications tools (e.g., e-referral, e-booking, e-discharge correspondence, clinical email/second opinion, laboratory test requesting/results reporting, e-shared care)
- Electronic networks (NHS-Net and disease specific clinical networking systems)
- Discipline/disease specific tools (e.g., diabetes informatics)
- Telemedicine applications (for interprofessional communication, patient communication and remote consultation)
- Subfields (e.g., nursing & primary care informatics)

Healthcare is primarily a people and location business. Rigid clinical roles, cultures and structures are detrimental to sustainable health systems. Technology is eliminating some jobs and creating new ones in informatics and pharmacogenomics. It is also opening up the possibility for more care to be delivered in outpatient clinics, offices and even homes but this is also has consequences on the doctor-patient relationship.

## 6. The consumer-driven Doctor-Patient relationship

Hospitals traditionally have required patients and doctors to come to them. Most hospitals were built on an inpatient model that has been expanded, remodelled and altered into consumer-unfriendly labyrinths. That original model is changing. Patients and doctors are finding other avenues for care provision that are more convenient, and technology ensures that caregivers connect to the best and brightest doctors globally.

Moreover, there is growing evidence that the current health systems of nations around the world will be unsustainable if unchanged over the next 15 years. Globally, healthcare is threatened by a confluence of powerful trends – increasing demand, rising costs, uneven quality, misaligned incentives. If ignored, they will overwhelm health systems, creating massive financial burdens for individual countries and devastating health problems for the individuals who live in them.

ICT is an important enabler in resolving healthcare issues such as integrating care and improving information sharing, when there is system wide and organisational commitment and investment. But IT is not a solution in and of itself. Of equal importance is improving patient safety and restoring patient trust.

There is also a significant, bi-directional influence on the patient-clinician relationship. "54% of patient-type respondents have discussed the results of their Internet searches with their care providers (n=533). Our results are confirmed by a recent study, from Harris Interactive [33 ], reporting that a majority (57%) of American adults, who have gone online to get health information, say that they have discussed this information with their doctor at least once. We report, among those who discussed the results of their Internet searches with their care providers, 95.8% (n=334) enjoy obtaining health information from the Internet and some 78.3% said ensuing discussions with their care provider were helpful because it improved doctor-patient communication, a huge increase of 40% compared to 2002 (38.3%, n=796). Most patient-respondents (88.2%) agreed that seeking health information on the Internet improves the quality of consultation with their physician. More than half (53%) of them use the Internet to seek a second opinion about a medical diagnosis. It is important to note that the majority of patient-respondents (90%) said that health care providers should suggest trustworthy online sources of health information. As the other player in the patient-physician relationship, health professionals had a receptive and positive attitude toward this behaviour, professionals' responses to these questions confirm previous patient-respondent results. Like patient respondents, medical professionals agreed by 77% that patient health information seeking on the Internet improves the quality of patient consultation." [34] Doctors can be essential in that they can "prescribe" information to the patient. [35] [36]

Prescribing doctors have a key role in ensuring patients have adequate access to information and helping them to interpret this information. Health services are responsible for ensuring the information exists and is reliable and accessible. Pharmaceutical companies have the greatest repository of data on their drugs, but their impartiality may be questioned. Special interest groups (charities, pressure groups) may have their own agendas to protect. Doctors, particularly general practitioners (who often can build on long term relationships with patients), must take a lead in information sharing with patients. There will be understandable concerns about the need for yet more time for yet more clinical tasks. It seems logical, however, to argue that early engagement of patients in decision making about treatment should prevent much subsequent morbidity and confusion and may, even in the short to medium term, save time as well as improve outcomes. [26]

When patients assume a greater role in acquiring medical knowledge, there must be a corresponding change in the doctor's role as treatment decision-maker. Additional dynamics are likely to result from different doctor behaviors, including embracing, avoiding, or disregarding Internet-derived information. To better define this variable, surveys and observational studies are needed that will elicit doctor attitudes toward Internet health information and their corresponding patient-doctor relationships. In addition, research is needed to evaluate the barriers to doctor implementation of information technology. In Canada, researchers have administered a new survey instrument to stratify primary care doctors into different levels of information technology usage. This approach may allow for specifically tailored strategies to be used in implementation. [36]

With the advent of user-generated health care, studies need to focus on defining steps towards sustainability by understanding its impact on global healthcare trends and how it will influence future health spending. "solution drivers" need to be identified within the control of executives and administrators, where health leaders can take action and effect change, serving as a call to action for healthcare organisations to look beyond their own boundaries to tackle the complex challenges of integrating user-generated health care and its sustainability impact.

In our view, the following is needed:

- A *common vision and strategy* to balance public versus private interests in building an infrastructure and in providing basic health benefits within the context of societal priorities.
- *Better use of technology* and interoperable electronic networks to accelerate integration, standardisation, and knowledge transfer of administrative and clinical information.
- *Incentive systems* that ensure and manage access to care while supporting accountability and responsibility for healthcare decisions.
- *Defined and adopted clinical standards* need to be established with mechanisms for accountability and enhanced transparency, thereby building consumer trust.
- *Optimised resource allocation* that appropriately satisfies competing demands on systems to control costs while providing sufficient access to care for the most people.

*Innovation, technology and process changes* are a means to continuously improve treatment, efficiency, outcomes and governance but these must be taken into context of *flexible care settings* and *expanded clinical roles* that provide avenues for care that are centred on the needs of the patient.

## 7. Conclusion

Modern Healthcare Systems that have embraced Internet technologies (referred to as Health 1.0) are evolving towards self management from a clinical knowledge perspective. In contrast, patients are using the latest web 2.0 technologies and developing healthcare social networking communities (referred to as Health 2.0) which are evolving towards becoming online medical portals. The developing Grand Challenge in healthcare is therefore how Health 1.0 will work together with Health 2.0 in a consumer market place to deliver personalised self management services.

The locus of power in health care is shifting: instead of the doctor acting as sole manager of patient care, a consumerist model has emerged in which patients and their doctors are partners in managing their care. The self care information tool of the future will be a combination between the patients observation record and the Internet, with the doctor and the patient positioned together at the intersection but not having to pay attention to the technology.

Consumers will assume greater responsibility for choosing their health benefits and providers. Moreover, the availability of easily accessible information will be at the core of any consumer driven healthcare model. However, whether the Internet can actually empower patients and enrich the patient-doctor relationship is still undecided. Furthermore, with the advent of user-generated health care its impact on global

healthcare trends and influence on future health spending needs to be understood in order to tackle the complex challenges of integrating user-generated health care and its sustainability impact.

## 8. References


[1] "HEALTHCAST 2020: Creating a sustainable future", PricewaterhouseCoopers , December, 2006.
[2] "Healthcare and Smart housing technologies", Report of a DTI International Technology Services mission to Japan, 14-18 February 2000.
[3] Digital healthcare: the impact of information and communication technologies on health and healthcare, Royal Society 2006, http://www.royalsoc.ac.uk/news.asp?id=5690.
[4] ETSI Report 2005: "Human Factors (HF) in Telecare services: Issues and recommendations for user aspects", ETSI DTR 102 415 (2005-06-15). Available from http://portal.etsi.org/stfs/hf/STF264.asp
[5] The MATCH projects focus on a number of perspectives: manufacturers, regulators and users. Project 3 in particular is about engaging with users. See http://www.match.ac.uk
[6] 9th "Health on the Net Survey of Health and Medical Internet Use" http://www.hon.ch/Survey/Survey2005/res.html
[7] Health and ageing in the knowledge society: employment, social cohesion and e-health potential. Working document of the high level group on employment and social dimension of the information society (esdis) 2006 http://ec.europa.eu/employment_social/knowledge_society/docs/healthinks_20060429_esdis.pdf
[8] L. Bos, Medical and Care Compunetics the Future of Patient-Related ICT, Medical and Care Compunetics 4, L. Bos et al, IOSPress 2007, pp. 3-17, http://www.icmcc.org/pdf/bosios2007.pdf
[9] Experts Patient Programme, http://www.expertpatients.nhs.uk/what.shtml (accessed July 26, 2006)
[10] The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century, UK Department of Health, 2001. http://www.dh.gov.uk/assetRoot/04/01/85/78/04018578.pdf
[11] Trevor Jones, Foreword to the Expert Patient, The Association of the British Pharmaceutical Industry, http://www.abpi.org.uk/publications/publication_details/expert_patient/foreword.asp
[12] Glin Bennet, Patients and their doctors : the journey through medical care, 1979
[13] Joanne Shaw, Mary Baker, "Expert patient"—dream or nightmare?, editorial, BMJ 2004;328:723-724, http://bmj.bmjjournals.com/cgi/content/full/328/7442/723
[14] Joseph Conn, Health 2.0: The next generation of Web enterprises, Modern Healthcare, December 2007, http://www.modernhealthcare.com/apps/pbcs.dll/article?AID=/20071211/FREE/312110003/)
[15] Swamy Laxminarayan, Foreword, Clinical Knowledge Management, Opportunities and challenges, R. Bali, 2005.
[16] The Harris Poll® #76, July 31, 2007, http://www.harrisinteractive.com/harris_poll/index.asp?PID=792
[17] A. Risk, J. Dzenowagis, Review of internet health information quality initiatives, J. Med. Int. Res. 3 (4) (2001) e28, http://www.jmir.org/2001/4/e28/.
[18] Gunther Eysenbach, MD; John Powell, MSc, MRCPsych, MFPHM; Oliver Kuss, PhD; Eun-Ryoung Sa, MS, Empirical Studies Assessing the Quality of Health Information for Consumers on the World Wide Web A Systematic Review JAMA. 2002;287:2691-2700 http://jama.ama-assn.org/cgi/content/full/287/20/2691
[19] Ask the patients—they may want to know more than you think David Dickinson, D K Theo Raynor BMJ 2003;327:861–4
[20] A. Risk, J. Dzenowagis, Review of internet health information quality initiatives, J. Med. Int. Res. 3 (4) (2001) e28, http://www.jmir.org/2001/4/e28/
[21] 9th "Health on the Net Survey of Health and Medical Internet Use" http://www.hon.ch/Survey/Survey2005/res.html
[22] http://www.who.int/hinari/en/
[23] http://www.inasp.info/health/index.shtml
[24] http://www.htai.org/
[25] http://www.eahil.net/index.htm
[26] "Doc, tell me what I need to know"- a doctor's perspective, james G. Kennedy, BMJ 2003, 327; 862:863
[27] Presentation on websites of possible benefits and harms from screening for breast cancer: cross sectional study, Karsten Juhl Jørgensen, Peter C Gøtzsche, BMJ 2004;328;148ff, doi:10.1136/bmj.328.7432.148

[28] Brownsell, Simon; Blackburn, Steven; Hawley, Mark S., An evaluation of second and third generation telecare services in older people's housing, Journal of Telemedicine and Telecare, Volume 14, Number 1, January 2008, pp. 8-12(5)
[29] B.R.M. MANNING, J. McCANN, S. BENTON, J. BOUGOURD, Active Ageing: Independence through Technology Assisted Health Optimisation, Medical and Care Compunetics 5, IOSPress 2008
[30] J. Verhoef, P.J.Toussaint, T.P.M. Vliet Vlieland, J.H.M. Zwetsloot-Schonk, The impact of structuring multidisciplinary team conferences mediated by ICT in the treatment of patients with rheumatic diseases, in: Medical and Care Compunetics 1, L. Bos et al., 2004
[31] Pagliari C, Sloan D, Gregor P, Sullivan F, Detmer D, Kahan JP, Oortwijn W, MacGillivray S, What Is eHealth (4): A Scoping Exercise to Map the Field J Med Internet Res 2005;7(1):e9, http://www.jmir.org/2005/1/e9/
[32] Norman CD, Skinner HA, eHealth Literacy: Essential Skills for Consumer Health in a Networked World, J Med Internet Res 2006;8(2):e9, http://www.jmir.org/2006/2/e9/
[33] Number of "Cyberchondriacs" – U.S. Adults Who Go Online for Health Information – Increases to Estimated 117 Million, David Kran, Harris Interactive, HealthCare News, 2005, http://www.harrisinteractive.com/news/newsletters/healthnews/HI_HealthCareNews2005Vol5_Iss08.pdf
[34] 9th "Health on the Net Survey of Health and Medical Internet Use" http://www.hon.ch/Survey/Survey2005/res.html
[35] Donald W. Kemper, Molly Mettler, Information Therapy, 2002; www.healthwise.org
[36] Gerber BS, Eiser AR, The Patient-Physician Relationship in the Internet, J Med Internet Res 2001;3(2):e15, http://www.jmir.org/2001/2/e15/
[37] Diagnostic, Monitoring and Assistive Tools, Devices, Technologies and Equipment to Support Self Care, Full review report, Department of Health, UK, August 2005.
[38] S Shoor, KR Lorig, Self-Care and the Doctor-Patient Relationship, Medical Care. 40(4) Supplement:II-40-II-44, April 2002
[39] http://www.bigmouthmedia.com/live/articles/social-networking-sites-are-uk-hit.asp/4155/
[40] Ahmad,F, HudaK.P.L, BercovitZ.K. Hollenberg. E, Levinson,W. Are Physicians Ready for Patients With Internet-Based Health Information? ***(J Med Internet Res 2006;8(3):e22)*** doi:10.2196/jmir.8.3.e22
[41] http://www.health.am/cr/more/online-information-may-improve-cancer-patients/
[42] P. C. Tang, J. S. Ash, D. W. Bates, J. M. Overhage, D. Z. Sands,Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption, J Am Med Inform Assoc**.** 2006;13:121-126. DOI 10.1197/jamia.M2025, http://www.jamia.org/cgi/content/full/13/2/121
[43] Frauke Sinclair, In Need of TLC? A Doctor-Patient Relationship Fit for the Future, Scottish Council Foundation, 2007, http://www.scottishcouncilfoundation.org/page.php?id=25

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# National and Regional Projects

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# TELEMEDICINE ENDURANCE-EMPOWERING CARE RECIPIENTS IN ASIAN TELEMEDICINE SETUP

Mr. Jagjit Singh BHATIA[a], Ms. Sagri SHARMA[b]
[a] *Director, Center for Development of Advanced Computing*
*(A Scientific Society under Ministry of Communications & Information Technology Govt. of India)*
*A-34, Industrial Area, Phase VIII, Mohali, Punjab – 160071*
*Phone: +91-172-2237052-57 Fax: +91-172-2237050/51*
*Email:* jsb@cdacmohali.in
*Website:* http://www.cdacmohali.in. & www.esanjeevani.in
[b] *Assistant Engineer, Center for Development of Advanced Computing*
*(A Scientific Society under Ministry of Communications & Information Technology Govt. of India)*
*A-34, Industrial Area, Phase VIII, Mohali, Punjab – 160071*
*Phone: +91-172-5096521 Fax: +91-172-2237050/51*
*Email:* sagrisharma@cdacmohali.in
*Website:* http://www.cdacmohali.in.& www.esanjeevani.in

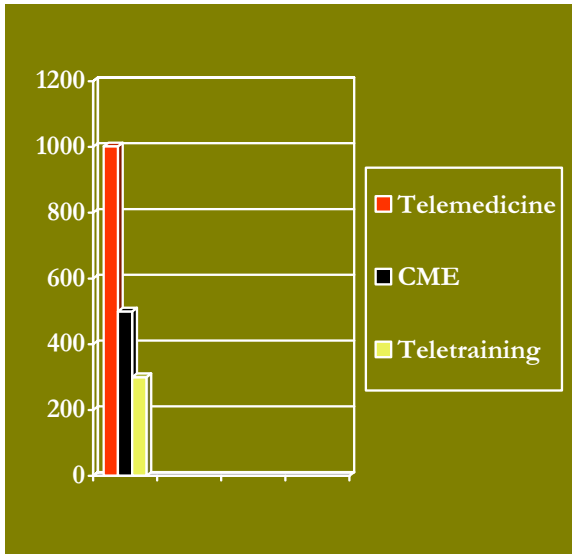
**Abstract**. To optimize the medical resources in India and Asia empowering the patients with e-health services in order to justify the multi-specialty healthcare provided to the rural and remote areas is the need of the hour. C-DAC Mohali is working in this direction since 1999 and deployed the technology for the amelioration of the rural Indian population. We bring home the bacon by a broad spectrum of professional quality Telemedicine products and customized solutions that fit within any budget constraint. We're experts in telemedicine conferencing and can help find the right solution to empower the patient with the essentials tools. Through this paper a description of the results from our Telemedicine projects, with substantiating and quantifiable data is put forth. Indian Telemedicine establishments need periodic evaluation to rationalize the main objective of the technology i.e. patient care, patient satisfaction, and patient opinion – in one word – patient empowerment.

**Keywords.** Telemedicine, telemedicine implementation, hurdles, medical referral System, ICT, patient empowerment.

## 1. INTRODUCTION

C-DAC Mohali pioneered in the field of Telemedicine in the northern India by developing and implementing its in-house state-of-the-art Telemedicine application software solutions namely Sanjeevani and e-Sanjeevani [9]. The solutions where customized based on end user requirements abide by international standards [10] and the results thus obtained were overwhelming. The data below speaks for us:

| | |
|---|---|
| Telemedicine | 1002 |
| CME | 500 |
| Tele-training | 300 |

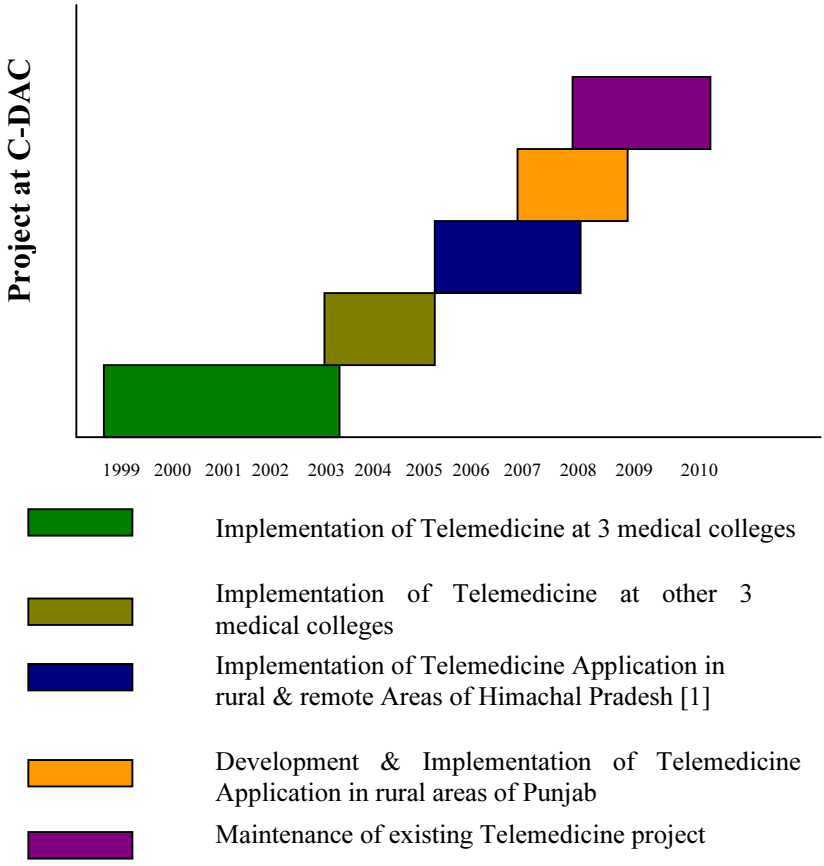



*1.1. Aim and Objectives of C-DAC Mohali's Telemedicine initiative:*

- Provide Super-specialty Timely Health Care to the common man at an affordable cost.
- Lessen the health care burden from the surrounding states at Medical colleges and other super specialty Hospital using ICT.
- Evolve a streamlined referral system
- Integrate the private and Govt. health care resources
- Optimize and multiply the limited health care resources
- Integrate health care with e-Sampark (the e-Governance centers [11] )
- Extend to Community Centers, Old age homes, Schools and common man's Home.
- Assist in providing continuous Medical Education and spreading awareness programs.
- Education of nursing and Para-medical staff and providing technician training [2] and tele-medicine for the rural population can strengthen trained manpower resources in the rural areas
- Develop Healthcare Management Information System

During this voyage, we faced hurdles that didn't deter our team from the goal; rather they acted as catalyst in the overall success of the project. To name some; software development hurdles, User Testing hurdles, Networking problems, Government agency reluctance, project implementation hurdles, budgetary issues.

We have till date implemented five projects as depicted in figure below:

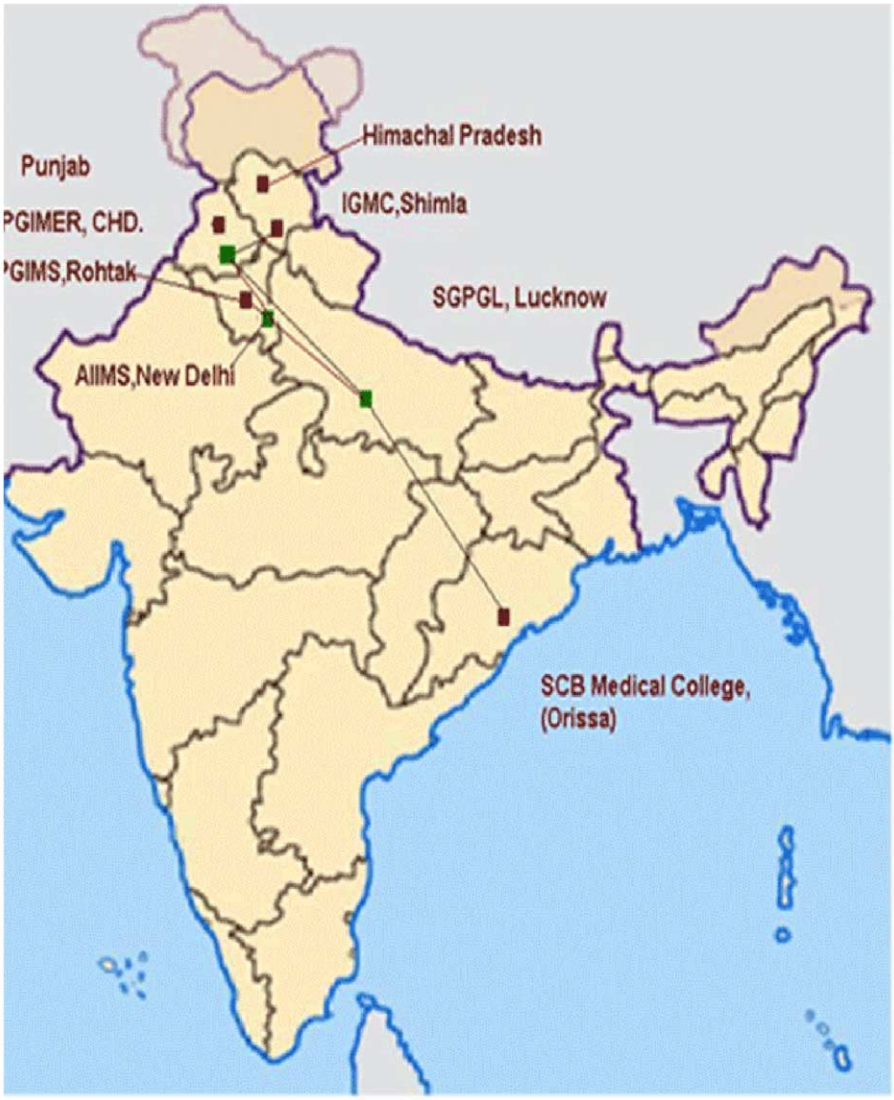



The maiden project laid the foundation of Telemedicine in India by connecting three major Medical institutions namely PGIMER Chandigarh, SGPGIMS Lucknow and AIIMS New Delhi. The network technology then used was ISDN connectivity and the speed was 384kbps for video conferencing and data transfer.

But the main objective of Telemedicine was not met by this connectivity as it didn't involve any expert consultation for the benefit of rural population in India.

To further the journey and with the above said objective in mind, C-DAC Mohali under the aegis of Department of Information and Technology (DIT) [6] connected another three medical institutions namely IGMC Shimla [4], SCB Medical college Cuttack and PGIMS Rohtak.

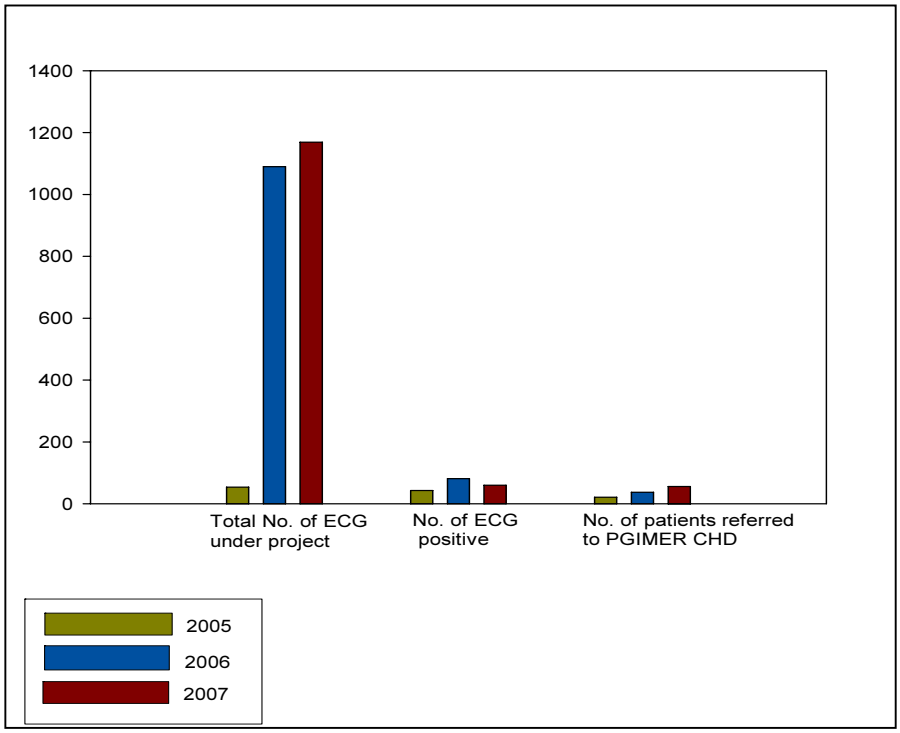
The network diagram is shown below.




This extension of the network increased the usability many a folds and we managed to provide health expertise to the needy.

By 2005 the Himachal Pradesh Health Systems [5] shakes hands with us and we bagged a multi crore project from the government. This project totally met the objective as the people of the state were benefited immensely.

The data for the ECG done at different locations collected over a period of 2 years is shown below.



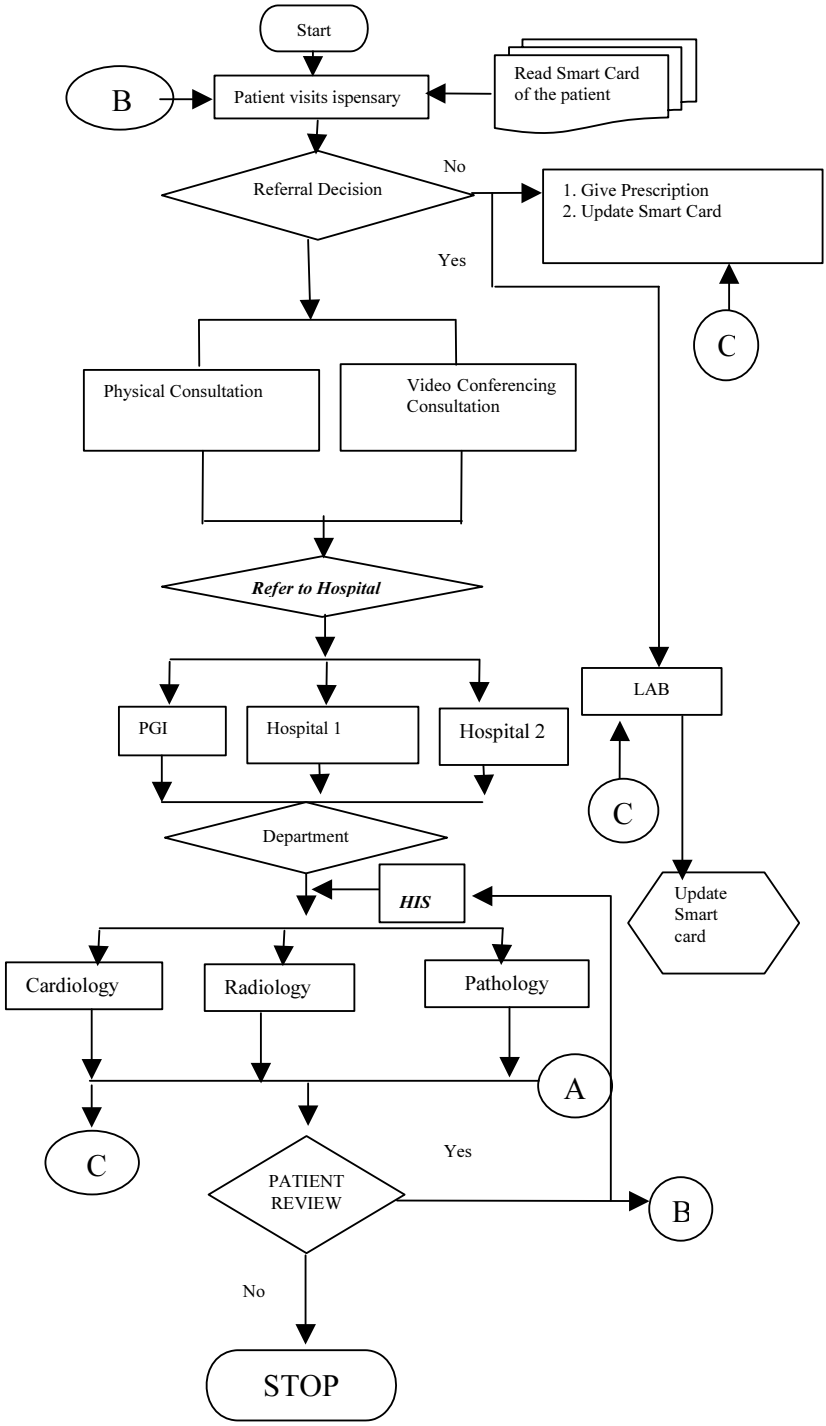

Impressed by the success of the Himachal Pradesh project, Punjab Health Systems Corporation Mohali Punjab looked up to C-DAC Mohali for a similar project, making total working Telemedicine sites up to 30, that will cross 50 by November 2008.

## 2. STREAMLINING OF 'MEDICAL REFERRAL SYSTEM'

To streamline the healthcare services and make the multi-specialty healthcare readily available to the common man, C-DAC Mohali outlined a streamlining of referral system as depicted below: This has enable the achievement of the Healthcare vision of the health ministry of the Indian Government [6].

## 3. C-DAC MOHALI'S CONCERNS

As mentioned before, we faced tremendous hurdles [3] during all these projects. Major factor for which is the non-availability of policies for managing the Telemedicine and attitude of the hospital management. Enough technology is available for use and is very




Suggested Referral System

user friendly as well as cost effective. The developer and researchers can only provide technical facility and organize infrastructure to facilitate user. The users are trained under expertise and well equipped to use the telemedicine for the patients. Health authorities are required to formulate a policy to manage the same. IT department of states are required to create a special Telemedicine division with efficient managers.

At present in India, telemedicine is a separate department altogether and doctors have to visit the department to explore telemedicine, i.e. the telemedicine infrastructure is remotely located.

The hospital need to network the doctors through LAN so that every doctor has a telemedicine access on his work table through a central access system. This will develop interest of doctor as well as boost the usage of telemedicine based software solution for patient benefit.

Definitely this step will enhance the usability of the medical facilities by just putting ICT in place. Telemedicine is the best example of ICT. Similarly, technical group who can extend this facility up to the point when the services are registered in emergency, are very much needed. This technical force shall be trained in network technology, communication, and PC maintenance and providing support for solving the software problem as well as understanding of the optional faults in medical equipment. This pool of professional are required not only to handle the emergency or disaster but also required to maintain the state wide Telemedicine network.

## 4. HINGES IN THE SUCCESS

- Software development hurdles: Telemedicine software development required programming expertise as well as doctor's consultancy for the fruitful results. We need to outline the overall structure of the module under development and so the requirement analysis phase is the most stringent and time consuming. Medical specialist's interest and dedication is mandatory. As far as our experience is concerned, the response from specialist is a mixed bag. Some of them are really interesting in implementing telemedicine in their set up while others are inert.
- Doctor's reluctance towards the use of Technology: In particular, Sanjeevani- A Telemedicine application Software solution- couldn't be applied as expected due to resistance from doctors towards using PC based equipment and telemedicine to diagnose a patient as they are more used to their conventional ways. Secondly, it was delayed because the doctors didn't have sufficient time, which they could devote to telemedicine.
- Networking problems: We aim to provide the latest in the communication technology to facilitate seamless connectivity between all the Telemedicine sites. For instance, in the Punjab Telemedicine project we aim to connect all the 23 sites through VPN over broadband, but the technology is quite advance and only BSNL [7] is capable to provide the same at most of the locations. Also, the maximum bandwidth provided by them is only 512 kbps against the maximum stated 8 Mbps. We left no stone unturned to increase the bandwidth to 1 Mbps by scheduling meeting with senior BSNL officials and making our requirements as a special case. Still the connectivity is an issue at some of the locations.

- Project implementation hurdles: Difficult terrain, extreme whether conditions, lack of technical manpower, local hindrance factors are some unavoidable circumstances which causes project delay.
- Government agency reluctance: As mentioned in the networking problems, the government bodies like BSNL [8], Health departments etc are difficult to work with as they are bound with certain rules and procedures which delay the course of action which can be otherwise taken quickly.
- Budgetary issues: We reduce the budget of the project to be submitted to the Department of information and Technology New Delhi by opting for low cost equipment. But there is always a trade off between quality and cost. Low cost equipments are not that sharp and precise to meet the doctor's requirement and so the overall quality of the Telemedicine system reduces.

## 5. CONCLUSION

Telemedicine is used to describe the application of Information and Communications Technologies (ICT) to the healthcare segment and create an efficient system, to provide better and safer patient care. Internet has the potential to revolutionize healthcare by providing unprecedented access to information. Millions of people worldwide are using the internet to obtain quality healthcare information directly affecting their lives, making this form of healthcare an important tool for improving health. By analyzing the outcome from different applications of Telemedicine we can overcome the challenges in the successful implementation of the technology and reach the destined pinnacle of patient empowerment.

There is a growing interest in theories of empowerment in health care among Indians. Patient's empowerment may be seen as a way of operationalizing user participation in the health sector. However, there is more to the interest in the concept of empowerment than this. A need for local symptom management and prevention may be emphasized and this may in turn indicate that mobilizing the patients' own resources is important for successful implementation of health promotion activities. It is an inherent aspect of such lines of reasoning that professional medical competence and peer knowledge are taken to be complementary resources in this respect and that the patients' own experience may be extensively drawn on in all prevention and treatment. Patient knowledge concerns local ways of illness prevention and responsibility for personal health. Such knowledge also concerns the tackling of lasting of chronic symptoms within the local environment. For the patients themselves local knowledge and self-help build on the sharing of coping strategies among peers.

The concept of empowerment appears to be the process of enabling individuals to take responsibility for personal health. The professional doctors often use the idea of empowerment in imparting tele diagnosis, tele-consultation and tele-education in order to increase control over and improve the health of the poor at remote places who can't gain access due to costs, time and other climate factors. Since the meaning of empowerment is "to authorize" and "to enable", this implies shared responsibility between doctors at specialty hospitals and the doctors at the remote sites. The ideas of self-responsibility, self-determination and self-care, together with notions of personal control are summarized in the concept of empowerment of the individual. It is believed

that information technology can help doctors to think and act not only for the local patients but also for the patients at remote places by providing them correct and updated information at the right time. A positive self-esteem may be created as a consequence, which gives the doctors the ability to set and achieve goals, give a sense of control over the life of ailing patients at remote sites, and yield a sense of hope for the future.

Empowerment of patient to understand details of his or her own health status; to reach knowledge about preventive care and other services on after, so as to make correct decision; to be involved in his/her own process of care and be able to access specialty advice from doctors at various specialty hospitals and colleges; to be in easy contact and perform effective and good communication through their own doctors with the specialty doctors at the telemedicine sites so as to receive prompt and focused diagnosis and consultation advice. These are all the expectations to the impact of new ICT-based tools plus telemedicine software like Sanjeevani and e-Sanjeevani in tele health care.

## 6. REFERENCES

[1] J.S. Bhatia & S Sharma: "Telemedicine odyssey-Customized Telemedicine solution for rural and remote areas in India" The Journal on Information Technology in Healthcare 2006 http://www.hl7.org.tw/jith/
[2] E-learning Resource Manual. American College of Physicians, Annual Session 2003.
[3] Paul LD, Assessing Technological Barriers to Telemedicine: Technology- Management Implications. IEEE Vol. 46, No. 3, August 1999
[4] http://www.igmcshimla.org
[5] http://himachal.nic.in
[6] http://www.mit.gov.in
[7] http://www.bsnl.co.in
[8] http://www.hp.bsnl.co.in
[9] JS Bhatia, S Sharma, MK Randhawa: "eSanjeevani- A Web Based Telemedicine Application Software" at the International conference on Emerging Technologies, ICET 2006 Peshawar, Pakistan. http://icet2006.org/
[10] JS Bhatia, S Sharma, MK Randhawa: "eSanjeevani: A Web Based Tele Medicine Application Abide By the Global Telemedicine Standards" at the International Conference on The Hospital of The Future at Chicago, Illinois, USA http://www.hctm.net/events/2006/conference_2006.html
[11] Mr. Sanjay Sood & JS Bhatia on "eHealth accentuates eGovernance" 6th National Conference on eGovernance, 24-25 October 2002 at Chandigarh, India.

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# The Patient's Perspective in the Dutch National Technical Agreement on Telemedicine

Wouter J. MEIJER[a]
[a]*Partner ICTUS Netwerk, writing member NTA project group*

**Abstract** ..In 2007, the Dutch National Technical Agreement (NTA) for Telemedicine was established.
Telemedicine deals with care processes.
The goals of Telemedicine were defined broadly, including quality of life in non-medical terms as seen from the patient's perspective: 1) independence, 2) self-reliance; 3) participation in society and social life and 4) self-determination (autonomy through freedom of choice) for the care consumer and his environment.
Quality aspects were defined at three levels:
1) patient level Telemedicine must be in line with his needs
2) level of information provision, such as: patient's rights in information control were also defined in the NTA: the care consumer has ultimate control over his own data. The care consumer decides who, in which functional capacity within the care process, is entitled to access which data at which level (reading) and is entitled to process it in some way: making additions, changes or possibly deleting (writing). On request, the healthcare provider must allow the care consumer access to his own data as quickly as possible and/or provide a copy of (part of) the record.
3) level of business processes, e.g.it is important that the care process is designed on the basis of statutory requirements for the allocation and registration of the roles, rights and obligations of all actors concerned.
For quality assurance, the processes must be defined on the basis of the function that they perform in the achievement of the goals (intended outcome), from the starting situation (input). The intended outcome means that the needs or requirements of the involved parties are fulfilled.
The quality of the Telemedicine service must be assured in a cyclical and ongoing process. This can best be done by developing a quality management system based on indicators and criteria for quality.

**Keywords**. Telemedicine, Standard, Quality Aspects, Quality Assurance, Record Access, Information Control

## 1. Introduction

In the Netherlands, in November 2007, a Dutch National Technical Agreement (NTA) for Telemedicine, the NTA 8028 [1], was established [1]. The aim of the NTA is to improve communications between the various interested parties and to stimulate the application of Telemedicine in the Dutch healthcare sector.

[1] The NTA Telemedicine is available in Dutch and in English and can be ordered at bestel@nen.nl or by phone +31(0)152690882.

In the NTA, the background of Telemedicine was described:
'Applications that make use of ICT facilities are now finding their way into patients' and clients' homes. New forms of care provision will be needed if the demand for care is to be satisfied at an affordable price. Telemedicine is one example of such a new form of care provision. Situations in which telemedicine is being used are typically those in which actors at various locations actively cooperate in a particular process.'

The need for a normative document for Telemedicine was felt since in the international norms and standards of ISO and CEN there was not yet a comprehensive normative document on Telemedicine.

The NTA was drawn up with the following users in mind:

- the care consumer and the person providing it, the most important actors in the actual care process supported by telemedicine;
- parties that are not directly involved in the telemedicine process but which do have an impact on it; such parties include industry, knowledge institutions, healthcare insurers, official supervising agencies, government, policy makers, sectoral organizations, associations of patients, scientific associations and healthcare institutions.

In the NTA the needs of all involved parties are acknowledged. This paper in view of the scope of the ICMCC congres, focuses on aspects of the NTA that are most relevant for patient empowerment.

The NTA has been developed by a project group that consisted of public and private organizations in the healthcare field.

The NTA has the status of framework document; it covers the whole area of Telemedicine, and addresses three key issues: definition, goals and quality aspects. Specific quality requirements for Telemedicine fall beyond the scope of the NTA. We are preparing a project for the development of a subsequent Dutch norm for Telemedicine. That norm will describe quality requirements from these generic quality aspects.

The Netherlands Standardization Institute (NEN) will attempt to initiate a European Telemedicine Norm of the CEN. Such a norm would take the Dutch Telemedicine.norm into account. The Dutch NTA and (in the event that a European standard is established) the European standard could be a support for movements in other countries to define patient's rights in access to medical records and information control.

In this paper, the quotations from the NTA (in an English translation that has not been formally authorized) are between quotation marks.

## 2. Uniformity on What Is Meant by Telemedicine

Present definitions vary widely. Some call Telemedicine all ICT applications in healthcare. Others call Telemedicine all ICT applications with direct patient use and involvement. Others mean by Telemedicine all applications using communication facilities like the internet or mobile communication.

Normalization can contribute to the alignment and harmonization of telemedicine activities. For parties in the healthcare sector it is therefore important to define telemedicine more clearly. A widely accepted definition of telemedicine is also of importance for a safe, speedy and socially acceptable introduction of the phenomenon.

***The Dutch definition of Telemedicine is as follows:***

**'Telemedicine is a care process or the whole of the care processes which satisfies each of the following criteria:**

- the effect of distance is reduced by the use of information technology and telecommunications;
- there are at least two actors involved, at least one of whom must himself be an accredited healthcare practitioner (in the definition of the Individual Healthcare Professions Act [BIG Act])[2] or must be acting under the responsibility of an accredited healthcare practitioner.'

The definition can be used to establish what is called Telemedicine, which (future) applications should comply with the minimal set of requirements. Many of the present IT applications do not fit the definition and as such are left out of the NTA discussion.

## 3. Goals of Telemedicine

The goals of Telemedicine were not only defined in terms of quality of care and quality of service such as improved health situation and a better fit with the wishes, needs and expectations of care consumers and informal carers. They were also defined in terms of quality of life, seen from the patient's perspective:

- increased and extended independence;
- increased and extended self-reliance;
- improved participation in society and social life
- improved self-determination (autonomy through freedom of choice) for the care consumer and his environment.'

## 4. Quality Aspects

A minimal set of requirements has to be applied to any telemedicine application from the perspective of the different users, application builders and providers/facilitators.

The minimal set of requirements can be developed from the perspective of users (such as patient, care giver).from the perspective of information provision (the main argument to use telemedicine) from the point of view of the business process and last – but not least – the organizational structure. There where actors (people like caregivers, patients) communicate in different ways the organizational structure has to follow this change.

### *4.1. Patient Orientation*

'Just like the normal care process, telemedicine is aimed at improving the health, the self-determination, the self-reliance and/or social functioning of the care consumer. Telemedicine must be in line with the realistic needs of the patient.'

### *4.2. Quality at the Level of Information Provision*

'There is always a risk that the use of ICT could cause information to be distorted or unduly distributed, either intentionally or inadvertently. Actors must therefore make sure that adequate security measures have been taken to protect both information and information streams. The following aspects play a role in this context:

- confidentiality. Data must only be accessible to authorized persons;
- integrity. Information must have integrity, i.e. it must be reliable. Data must not be distorted or otherwise damaged by the information system;
- availability. Data must be available to the user at the right place and at the right time, throughout the statutory retention period. The fact that technology can never be 100% reliable makes it necessary to pay attention to the issue of continuity in the event of any failure or disruption;
- non-repudiation and accountability. It must be clear who has entered or accessed which data;
- usability. The data must be usable for the purpose for which it is intended;
- interpretability and analysability. The data must be unambiguous;
- selectivity. The data are selected and consequently suitable and accurate for the appropriate purpose.

Quality demands on the user equipment and peripheral equipment used for telemedicine, information security at the workstation and the secure transport and storage of data, all form part of the overall security and safety of telemedicine.'

#### *4.2.1. Control of Data*

'The care consumer has ultimate control over his own data. The care consumer decides who, in which functional capacity within the care process, is entitled to access which data at which level (reading) and is entitled to process it in some way: making additions, changes or possibly deleting (writing). On request, the healthcare provider must allow the care consumer access to his own data as quickly as possible and/or provide a copy of (part of) the record (as set out in the Dutch Medical Treatment Contract Act) [3]. It is therefore essential that the process is designed on the basis of any statutory requirements for the allocation and registration of the roles, rights and obligations of all actors concerned.'

#### *4.2.2. Interoperability: Standardization and Connectivity*

'Telemedicine bridges distance and links actors at different locations who have different roles and responsibilities. This calls for interoperational systems whereby the actors and the systems themselves can communicate with each other. This requires standardization (CEN 13606 [4,5], ISO/TR 16056 [6,7], ISO/TS 16058 [8]) and connectivity.'

#### *4.2.3. User Convenience*

'The nature of telemedicine is such that it should preferably be capable of being seamlessly incorporated into the process in use by the user (whether healthcare provider or care consumer). The process and the basic functions must be adapted so as to be readily comprehensible to the user, after instruction and/or support where necessary.'

*4.2.4. Quality Aspects of an Information System*

'The quality aspects of information systems can be divided into a number of categories and this has already been done in ISO/IEC 9126 [9]. The principal characteristics of the quality of information systems are functionality, reliability, usability, efficiency, maintainability and portability.'

*4.3. Quality at the Level of Business Processes*

'Various aspects of legislation and regulation are applicable to business processes, e.g. facilitating business process security, the arrangement of the roles, the rights and the obligations of actors, the aim for interoperability between systems and the arrangement of certification for both processes and administrative organizations. '

*4.3.1. Process Description and Organizational Structure*

'An accurate description of the processes of care and the permanent availability of that description is essential. The description must take account of the definition of a "care process". According to various ISO standards (ISO 9000 [10] , ISO 9001 [11], ISO 9004) [12], processes must be defined on the basis of the function that they perform in the achievement of the resulting situation (outcome) from the starting situation (input). Outcome is taken to mean the desired final situation, i.e. the situation that fulfils the needs or requirements of the parties involved. This description must cover all processes and sub processes that are necessary to achieve that desired situation. It should also set out the relationships between the processes and subprocesses, in terms of sequentiality and interaction; the output of one subprocess serves as input for a following subprocess.

It is preferable that coordination and execution of the process should progress in accordance with predefined agreements and procedures. In order to assure both quality and transparency, the roles and rights of the actors involved must be known and be clear, namely: what can be done, how and when (role), and who may do what and when that may be done (right).

At least the following aspects play a role in this context:

- have procedures and protocols been written up and made known?
- has supervision been organized?
- besides being suitably competent, is the person processing the data (in the terms of the Dutch Personal Data Protection Act) also authorized to do so?'

EXPLANATION Under Article 1 (d) of the Dutch Personal Data Protection Act [13], the controller of the data is: "the natural or legal person or the administrative body which, alone or in conjunction with others, determines the purpose of and means for processing personal data." It is this controller who therefore determines the purpose of such processing and decides on the use of the personal data, the provision to third parties, the data retention period, etc. According to Article 1 (e) of the Personal Data Protection Act, the processor is the person or body which - on behalf of the controller, but not necessarily directly subject to his authority - processes the personal data in some way. The processor therefore processes data on behalf of the controller, i.e. in accordance with his instructions and under his responsibility, whether express or implied. The determining factor in the definition is the relationship with the entity responsible for data processing (the controller) and the degree to which the processing of personal data is accompanied by participation/control on the part of the processor.
(http://www.cbpweb.nl/downloads_uit/z2002-0362.pdf?refer=true&theme=purple)

*4.3.2. Responsibility and Administrative Management*

'Telemedicine can involve various actors, sometimes a large number, and they can be at different locations. It is therefore important to have a clear description of who is responsible for what process, or aspect of the process. Parties should be aware that the necessity to assure quality implies that minimum demands must be imposed on other actors in the care process. Those others sometimes stand outside the direct sphere of influence of the actors more immediately involved. It is therefore important that all parties recognize that potential risk and work together to reduce it to an acceptable level. The responsibilities of the various parties involved in telemedicine can be set out in contracts or agreements.'

EXPLANATION Specific risks are involved when one of the parties is a care consumer (in communication between the patient and the healthcare practitioner for example). The client or patient will often be in a domestic situation. The quality of the client/patient's activities is not guaranteed by legislation, whereas the healthcare practitioner does need to rely on the quality of those activities. Example: the care consumer provides information about the condition of his health and himself carries out measurements such as blood pressure. Specific supplementary measures then become necessary, such as regular checks of the equipment and of the care consumer's connection; attention must also be paid to correct use of the equipment and the devices used by the care consumer to take measurements.

## 5. Quality Assurance

*5.1. Internal Quality System*

'Any healthcare provider must monitor, manage and where necessary improve the quality of his service in a cyclical and ongoing process. This can best be done by developing a quality management system based on indicators and criteria for quality. The starting point for any improvement of quality must be determined on the basis of the needs of the parties involved.

With the aid of quality indicators in relation to the telemedicine process, and the outcomes of that process, the administrative organization can monitor the effectiveness and efficiency of both the care-related and the logistic process and report on the effects achieved. The monitoring and evaluation of quality indicators also provides information for users (healthcare practitioners and care consumers), healthcare providers, policy makers and healthcare insurers.'

*5.2. External auditability of the process*

'The quality of the care-related aspects of telemedicine can be assured by auditing systems, spot checks by professional bodies or by certification, all based on the quality requirements formulated by the parties involved.'

## 6. The Significance of the NTA for the Electronic Health Record

A question is whether an Electronic Health Record (EHR) 'is Telemedicine'. Strictly speaking, an EHR is not Telemedicine since an EHR is a (collection of) database(s),

while Telemedicine is a process. If an EHR is employed for a Telemedicine service, the EHR is a tool within the scope of Telemedicine.

## 7. How Can the NTA Be Put into Practice?

The first step is to check whether the NTA is applicable to the particular case (or area of applications), that is whether the above definition of Telemedicine is met:

1) Is it a care process?
2) Is distance bridged by information technology or telecommunications?
3) Is at least one of the actors an accredited healthcare practitioner (or acting under his/ hers responsibility)?

Secondly, the goals of the Telemedicine service are defined. Different actors have different goals that have been identified in the NTA (section 3).

Next, the processes of the Telemedicine service are described (or designed) as care processes, business processes and information processes (section 4.3.1).

1. *Care processes*
   The ultimate goal of the Telemedicine service is to fulfill the needs of stakeholders (in conformity with ISO 9004) or, in other words: achieving the desired outcomes. For healthcare a consistent set of outcomes has been defined by Donabedian [14]. The above goals of Telemedicine are in agreement with this. For instance, a description of care processes can make use of (among other things) the above mentioned goals for quality of life that were described from the patient's perspective (see section 3). When these goals are reached, the care processes have led to the corresponding desired outcome(s).
2. *Business processes*
   The business processes (e.g. data security measures) enable the care processes.
3. *Information processes*
   For the information processes: see section 4, e.g. the care consumer's right of record access and data control.

As the fourth step, measurable indicators of quality are deduced from the above goals. It is important that this is done systematically: firstly quality aspects are defined that are translated into quality requirements with measurable indicators and criteria of quality.

Quality aspects have been described in the present NTA but specific quality requirements fall beyond the scope of this NTA (the translation into quality requirements is subject of a planned following project, see Introduction).

Finally, the quality of the Telemedicine service can best be assured by a quality system. The quality system makes a cyclic process of quality improvement possible as well as (external) accountability of the Telemedicine service.

The above elements of the NTA are illustrated by the description of several Telemedicine applications in the ICMCC Congress book of 2007 [15].

## References

[1] NEN 8028: 2007 Health Informatics – Telemedicine The Netherlands, Delft; NEN, 2007
[2] Individual Healthcare Professions Act [*Wet Beroepen in de individuele Gezondheidszorg*, BIG]
[3] Medical Treatment Contract Act [Wet Geneeskundige Behandelovereenkomst, WGBO];

[4] EN 13606-1:2007 Health informatics – Electronic health record communication – Part 1: Reference model
[5] EN 13606-4:2007 Health informatics – Electronic health record communication - Part 4: Security
[6] ISO/TR 16056-1:2004 Health informatics – Interoperability of telehealth systems and networks - Part 1: Introduction and definitions
[7] ISO/TR 16056-2:2004 Health informatics – Interoperability of telehealth systems and networks – Part 2: Real-time systems
[8] ISO/TS 16058:2004 Health informatics – Interoperability of telelearning systems
[9] ISO/IEC 9126-1:2001 Software engineering – Product quality – Part 1: Quality model
[10] ISO 9000:2005 Quality management systems – Fundamentals and vocabulary
[11] ISO 9001:2000 Quality management systems – Requirements
[12] ISO 9004:2000 Quality management systems –Guidelines for performance improvements
[13] Personal Data Protection Act [Wet Bescherming Persoonsgegevens, WBP]
[14] Donabedian A. An introduction to Quality Assurance in Health Care. New York (NY): Oxford University Press; 2003
[15] Meijer, WJ, Ragetlie PL. Empowering the Patient with ICT-Tools: Bos L, Blobel B (Eds.) The Unfulfilled Promise. In: Medical and Care Compunetics 4. IOS Press, 2007

## Appendix A
## (informative)

### Registers of accredited professions in the Dutch healthcare sector

The above definition of Telemedicine mentions an 'accredited healthcare practitioner'. The list of practitioners to whom this applies is set out in Article 3 and Article 34 of the Individual Healthcare Professions Act [*Wet Beroepen in de individuele Gezondheidszorg Wet*, or BIG Act] [2].

The professions defined in Article 3 are those of pharmacist, physician, physiotherapist, healthcare psychologist, psychotherapist, dentist, obstetrician and nurse.

The professions defined in Article 34 are the paramedical professions. These are also mentioned in the BIG Act, although they are listed in a different register which can be found at http://www.kwaliteitsregisterparamedici.nl/. Registration is carried out by the Central Agency for Information on Healthcare Professions (CIBG) under instructions from the Quality Register for Paramedics [*Kwaliteitsregister paramedici*]. This register covers the following professions: pharmacy technician, dietician, occupational therapist, speech therapist, dental hygienist, Cesar and Mensendieck exercise therapists, remedial orthoptist, optometrist, podo- or posture therapist, radiodiagnostic technician, radiotherapeutic technician, dental prosthetician, and care workers providing healthcare in an individual setting (known in Dutch as VIG-ers).'

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*IOS Press, 2008*


# Electronic Health Records (EHR) in PROMED platform in accordance with the Romanian legislative framework

Roxana ANTOHI [a], Cristina OGESCU [a], Daniel BISTRICEANU [a] , Livia STEFAN [b], Silviu DUMITRU [b]
[a] *The Company for Research, Development, Engineering and Manufacturing for Automation Equipment an Systems -IPA SA, Bucharest Romania*
[b] *Institute for Computers- ITC SA, Bucharest Romania*

Abstract. The paper describes how the PROMED platform can be used as a Electronic Patient Record (EHR) system and also the platform's contribution to the improvement of the healthcare services in Romania as a solution for the integration of the main stakeholders involved in a National Healthcare System: patients, health care providers and public health authorities. By using the PROMED platform, the Public Health Authorities will be able to view various reports about the population health status and can elaborate timely prevention and warning plans in case of epidemic diseases.

**Keywords:** patient, electronic medical record , diagnosis , statistics

## Introduction

The main purpose of an electronic health record (EHR) is to support the multidisciplinary communication, cooperation and decision-making in the patient's care process. The basic characteristics of an electronic health record (patient-centered, longitudinal, comprehensive and prospective) can be acquired only in the context of an Integrated Care EHR in accordance with the a healthcare data management system .

The general principles which need to be considered by a healthcare data management system are:

- The responsibility of the Public Authorities for data collection, stocking and analysis;
- To provide specifications of the information flows;
- To ensure protection of the fundamental rights of the persons;
- To ensure the data security;
- To provide definitions of the data processing domain and conditions;
- To provide access of the deciding persons to the existing data and information;
- To ensure data confidentiality;
- To ensure access of the persons/patients to the general and healthcare information.

The implementation of the Promed Platform took into consideration these general principles.

## 1. General principles to which complies the PROMED platform regarding the healthcare data management

The PROMED multifunctional platform is implemented as a web portal application and so it is able to centralize data from different regions of the country from hospitals, ambulatories, private patient clinics etc. The Public Authorities can use the PROMED Platform to easily collect the data and view analysis by means of the "Medical statistics and research" module integrated in the Platform. This module is intended to present synthetic information regarding the health status of the comply population. Various reports are designed to be used for medical research and statistics and for healthcare providers reporting needs.

The reports comply with the privacy and confidentiality rules for medical data, revealing no information about individual patients.

The information flow is the following: minimal data patient is introduced in the platform; health providers when access the platform know if a patient is or not in the Platform Data Base by introducing the national personal identification number of the patient. The information which the health providers can access about the patient is vital and strictly necessary to evaluate the health status. It is possible to access the administrative data (name, surname, national personal identification number, residency and home address, phone, education level, occupation, healthcare insurance level) and information regarding the health status of the patient, namely the blood group, the Rhesus factor, chronic diseases, allergies to drugs or other substances.

The PROMED platform assures and protects the vital right of the persons.

The patient's identification is made by the national personal identification number. The patient data which is displayed on the computer is administrative data and information regarding the health status of the patient (the blood group, the Rhesus factor, chronic diseases, allergies).

In order to access the Promed Platform the patient receives a "patient accord" which must be completed by giving his name, surname, national personal identification number and e-mail. Also, the patient must express his accord regarding the registration of his health data in the platform.

The patient is the only who can access the entire health record by giving his user name and password, sent by e-mail by the platform's administrator following a patient registration.

The physician has access only to his patients and specifically to his patients' treatments. The patient has the power to give the physician access to her/his entire Electronic Patient Record only if he/she decides to.

The PROMED platform is able to process unitary the information regarding different kind of patient healthcare services, namely ambulatory treatment, family doctor consultation, hospitalizations in different hospitals.

The existing informatics' systems are accomplished for a specific hospital or for a private patient clinics and so the patient who needs his Electronic Patient Record has to

collect his record from each hospital where he was hospitalized or private patient clinic where he was in treatment.

By using the PROMED platform the patients will be able to visualize their healthcare evolution through a unitary Electronic Patient Record in a single request. The patients can also present to their current physician the Electronic Patient Records completed by other physicians. In this way the diagnosis decision process of physicians can be shorter.

The PROMED platform is a useful tool at the patient's disposal and also for correct diagnosis in case of an emergency (life risk situation) when the physician can access the platform through mobile devices (smart phone, PDA) by introducing the national personal identification number. The physician has access in this way to vital information regarding the health status of the patient, namely the blood group, the Rhesus factor, chronic diseases, allergies to drugs or other substances.

The main actors of the Health Informational System described in the legislation are: the Health Ministry, the National House for Health Assurance, hospitals, private consulting rooms, Public Health Institutes and Research Health Institutes. Each has an informational system more or less complex over which they exert exclusiveness. The consequence is report doubles and also incoherence in definitions and codifications.

As for the platform PROMED, the physicians can work directly with the *ICD-10-AM (OMS classification) Revision 2 / 2001 vol.1*, *ICD-10-AM* and also with the procedures for interventions in health field *Revision 3 / 2002 vol.3*.

In this way it is possible to eliminate the existing problems.

The Agreement foresights about data confidentiality are often violated in the medical practice for reason of control exerted by the Houses for Health Assurances. For example, the Houses for Health Assurances requests for some category of patients not only the national personal identification number, the diagnosis and the treatment, but also the name, the surname and the address, making easy the identification of the patient and violating the individual confidentiality.

In the Platform PROMED there is also implemented a **Medical statistics and research** module. This module is intended to present synthetic information regarding the health status of the comply population. Various reports are designed to be used for medical research and statistics and for healthcare providers reporting needs. The reports comply with the privacy and confidentiality rules for medical data, revealing no information about individual patients.

In the health field usual the data stored and the transmission of the data are achieved on the sheet or on a CD-ROM. The electronic evidence is often made late due to the data provider.

In the case of platform PROMED the data is stored on the server. There is a requirement that the entire database be read and copied to backup media. Oracle Recovery Manager (RMAN) has been recently enhanced to provide sophisticated backup and recovery services for huge databases. These enhancements mean that storing volumes of medical data in an ORACLE Database is now feasible.

## 2. The "Primary Care Electronic Patient Record"

This module is intended to be used by primary care providers (family doctors, ambulatory healthcare canters). This module manages all the data referring to the patients reported into the ambulatory, allows to view and modify various information from platforms database according to specific right access.

The module has access to the following information:

- patient's administrative data and "patient's anamnesis" section which manages the medical history data as it is declared by the patient in ambulatory;
- all the patient's data restrictive to emergency information: the major illnesses, allergies, i.e.; and the specific pathology (e.g. obstetrical anamnesis for women).

The module

- manages data about patient's health status during the treatments;
- manages patient data about the functional explorations prescription;
- manages patient data about laboratory analysis prescriptions;
- manages patient data about medication prescription during the treatments.

The information flow is the illustrated below:

After accessing the platform's site www.rommed.ro, the physicians enter the **Physician page.** The physician introduces the user name and the password (given by the Administrator). If the physician wants to change the password, he has this possibility by using the "Change Password" button. If the physician wants to see his patients will use the "**List Patient**" button and a list of patients will appear.

**Figure 2.1** "Primary Care Electronic Patient Record" module

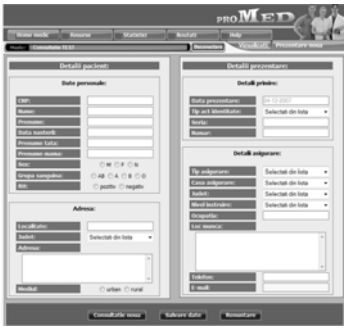

**Figure 2.2** a and b "Primary Care Electronic Patient Record" module

If a patient is present, the physician will introduce the national personal identification number. If the patient is already in the database, the minimal electronic patient record will be listed and the physician can update the record.

After saving the patient‘s data, the physician will open the window “*Examination details“.* During the patient’s examination the physician can update the patient‘s data and the patient’s anamnesis in the window “*Examination details”.*


**Figure 2.3** a and b "Primary Care Electronic Patient Record” module

In this window, the physician introduces the *“Sending details”* and the diagnosis from **CIM OMS REV 10 ED II** from pre-defined lists and also the physician’s name and paraph.

If all the introduced data is correct, the physician will use the ***“Save”*** button and the patient is introduced in the “ *Physicians examination list“.*


**Figure 2.4** "Primary care electronic patient record” module

If the physician will take the patient in treatment, he has the possibility to record the evolution of the patient in the “*Evolution*” window, which appears when it is selected a patient from the “*Physicians examination list“.*

The physician can prescribe medication during the treatment using the window “Medication” and also can prescribe functional explorations from ***CIM -1 AM ed 3 /2002.***

**Figure 2.5** a and b "Primary care electronic patient record" module

When the physician considers that he has all the data for the examination finalization, he will use the "Examination finalizing "button. The physician has the possibility to modify the first diagnosis to introduce new data about the patient, resulted from functional explorations. If the physician considers that he correctly recorded all the data, he will use the "Final Examination" button. As a consequence, the patient will disappear from the "*Examination list*" and will appear in the "*Patient list*" of the physician and the data about the examination will appear in the "*Patient"* page.

**Figure 2.6** "Primary care electronic patient record" module

## 3. The "Emergency "module

In case of an emergency (life risk situation), this module will allow the access to vital information regarding the health status of the patient, namely the blood group, the Rhesus factor, chronic diseases, allergies to drugs or other substances.

This module can be accessed only by authorized medical personnel without the patient's consent if he/she is unconscious or it is not able to give his/her consent. This module is designed to be accessed through mobile devices (smart phone, PDA).The display dates are essentially for the patient health status.


**Figure 3.1** a, b and c "Emergency " module

After the physician introduces the CNP (national personal identification number) of the patient, he will use the “Search” button. The vital data of the patient regarding the health status of the patient, namely the blood group, the Rhesus factor, chronic diseases, allergies to drugs or other substances will be displayed, making easier for the physician to take the right decision for the patient.


**Figure 3.2** "Emergency " module

## Conclusion

The PROMED platform represents an Internet access point and a web healthcare information system which provides various services for users (authentication, authorization, data and information management, reporting).

We consider the PROMED platform observes the general principles which need to be considered by a healthcare data management system.

The platform will be used to support the healthcare services involved in the diagnosis and decision process and to manage the electronic patient records.

The platform will allow:

- interaction between the three main actors in a health system:

  - the patients, who will actively track their own healthcare status and have an electronic patient record updated and available anytime and anywhere;
  - healthcare providers, who can find a patient and access its electronic patient record based on user access rights;
  - public health authorities, who will be able to view various reports about the population.
- health authorities to elaborate prevention and warning plans against diseases.

On the platform there are also publicly available information regarding healthcare providers and official indicators.

The PROMED Platform ensures the confidentiality of the data registration, the patient identification being made with the national personal identification number. The patients registration in the database it is performed following a patient signed an agreement.

The PROMED platform supports all the medical specialties.

We consider that the PROMED healthcare information platform will eliminate many current problems occuring in the national health system, ranging from paper format healthcare records managing problems to cooperation between healthcare providers.

In present we make experiments with PROMED platform in a pilot system with a 4G database. The PROMED Platform is being tested by physicians from two hospitals in Iassy and by physicians from Bucharest, Romania

In order to evaluate and improve the PROMED Platform, the experimental results will be presented and analyzed with the main authorities of the Romanian Health Informational System.

## References

[1] R. Antohi, C.Ogescu , L. Stefan, M. Raureanu, M. Onofriescu M Toma Management of the Electronic Patient Records In the WEB Based Platform for Diagnosis and medical Decision for Optimization in Helthcare -PROMED Technology and Informatics vol 127 IOS Press Amsterdam .Berlin .Oxford .Tokio. Washington 2007

[2] M Focsa UMF Timisoara Cadru legislativ romanesc in domeniul Evidentei Electronice a Datelor Medicale (EHR ) www.prorec.ro/PDF/Cadrul%20legislativ.pdf

[3].*** Stretgie post aderare post aderare 2007-2013 www.guv.ro/obiective /200701/strategie_post_aderare.pdf

[4] .**** Health Informatics: Interoperability of Healthcare Multimedia Report Systems, CEN TC251 WG IV, and Version 1, 1999-05-28.

[5] Charles E. Kahn jr**., -** Bringing Computer-Based Decision Support and Education to the Point of Care, Medical College of Wisconsin, 2004

[6] *** HL7 Clinical Document Architecture, Release Two, January, 2003, San Antonio, Texas;

[7] www.oracle.com

*Medical and Care Compunetics 5*
*L. Bos et al. (Eds.)*
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# Colorectal Cancer Screening – Using Informatics and Compunetics to Empower the At-risk Individual

Dr. Jeffery J. ARAMINI[1], PhD, MSc, DVM, Dr. Xiaohui ZHANG[2], PhD, MS, Mr. Michael L. POPOVICH[3], MS
*Scientific Technologies Corporation*

**Abstract:** Population-based cancer screening is most effective and cost efficient when offered through an organized screening program that incorporates all elements of the screening process, including information systems that support optimal program operation, monitoring, and evaluation. Although it is well accepted that organized population-based cancer screening programs can effectively reduce mortality, little effort has been invested in designing, developing, and implementing information systems to support these programs.
This paper presents a prototype information management system for organized population-based cancer screening. A typical colorectal cancer screening program was modeled for illustration of organized cancer screening workflow, key functional features were investigated, and a system infrastructure and architecture designed. The system as designed facilitates the sharing and management of information among the many stakeholders involved in the program (e.g., participant, family physician, specialist, hospitals, laboratories pharmacist). Throughout the functional design phase of this project, empowerment of the-at risk individual with access to personalized information and support was the core consideration. The leveraging of existing health records to facilitate risk profiling, and the proactive engagement and education of individuals with personalized information were considered key functional requirements of the system. The system was designed to provide participants with easy web-enabled access to view their status in the cancer screening program, and on-line resources to facilitate scheduling of activities, updating of personal profiles, and access to additional relevant information.
By proactively engaging individuals, providing them with personalized information, and facilitating their involvement in the cancer screening program with easy-to-use information management tools, the likelihood of program enrollment and participation will be greatly increased.

**Keywords.** Colorectal screening, compunetics, patient empowerment, health informatics.

[1] Public/Animal Health Epidemiologist, Director of Canadian Operations, Scientific Technologies Corporation – Canada, 8153 Side Road 15, RR3 Fergus, Ontario N1M 2W4, Canada, +1 519.766.3800 Jeff_Aramini@stc-canada.com
[2] Chief Scientist and Director of Asian Operations, Scientific Technologies Corporation, 4400 E. Broadway, Suite 705, Tucson, Arizona 85711, +1 520.202.3333, Xiaohui_Zhang@stchome.com
[3] CEO, Scientific Technologies Corporation, 4400 E. Broadway, Suite 705, Tucson, Arizona 85711, +1 520.202.3333, Michael_Popovich@stchome.com

## 1. Background

The goal of cancer screening is to reduce the cancer death rate by detecting health concerns early and increasing the likelihood of successful treatment. The key to successful population-based cancer screening programs is patient engagement and participation. Population-based cancer screening is most effective and cost efficient when offered through an organized screening program that incorporates all elements of the screening process, including evidence-based screening and follow-up guidelines, recruitment and retention strategies to maximize participation, as well as comprehensive quality assurance and information systems to support optimal program operation, monitoring, and evaluation. [1] The opportunity for health informatics to contribute to the success of population-based cancer screening is explored in this paper. The design of a prototype information system illustrates that by leveraging existing technologies and experiences with other health information systems, a cost-effective cancer screening information system is readily achievable.

Population-based screening programs, by their nature, have many elements potentially facilitated and enhanced through health informatics. For example, screening program participants need to be identified, invited to participate, tracked and monitored; test/procedure results must be managed; health care facilities and specialists need to be coordinated; and a variety of reports must be generated. In an effort to investigate the potential role of health informatics in a jurisdiction-wide cancer screening program, we chose a newly launched jurisdiction-wide colorectal cancer screening program as a model. Although most jurisdictions in North America have elements of organized screening programs for cervical and breast cancer screening, there are currently no information systems supporting colorectal cancer screening programs. [1,2]

Colorectal cancer is the third most common cancer diagnosed in both men and women in Canada. It is the second most common cancer-related cause of death for men and the third most common for women, with an estimated 4,600 deaths in men and 3,900 deaths in women in 2006. Scientific evidence suggests that colorectal deaths could be reduced by 17% if 70% of Canadians between the ages of 50 and 74 had a fecal occult blood test (FOBT) every two years. The prevalence of fecal occult blood test screening is currently low in Canadians aged 50 and over, ranging from 4% in women in Newfoundland and Labrador to 13–14% of men in British Columbia. In the U.S. in 2004, 26,881 men and 26,699 women died from colorectal cancer. [3] CDC suggests that as many as 60% of deaths from colorectal cancer could be prevented if people aged 50 or older were regularly screened.

## 2. Cancer screening program information system –functional requirements and solution design – Case Example Ontario, Canada

The Ontario jurisdiction-wide colorectal cancer screening program from which this prototype is based targets asymptomatic residents who are 50 years and older. A health informatics system is recommended to support the programs' screening model which includes rule-based decision support to monitor screening frequency, determined by risk profile. Ontario's program centers on average risk men and women who are invited to undertake a fecal occult blood test every two years, followed by colonoscopy if a positive fecal occult blood test results.

Individuals at increased risk because of one or more immediate family members with colorectal cancer and those with positive FOBT test results will be advised to undergo a colonoscopy. FOBT kits will be made widely available as part of an organized program through physicians' offices, primary care clinics, and group practices. People without family physicians will be able to pick up test kits from pharmacies or order them through a jurisdiction-wide Telehealth program. Patients will send completed kits to laboratories where they will be tested. An information system will invite individuals to participate, send reminders to individuals about screening, assist in result and follow-up notification for individuals without access to primary care providers, integrate and consolidate testing results, and evaluate the program's performance. The program will follow up and track screening results for people without access to a primary care provider. Figure 1 provides an example work-flow diagram outlining some basic elements in supporting a colorectal cancer screening program.

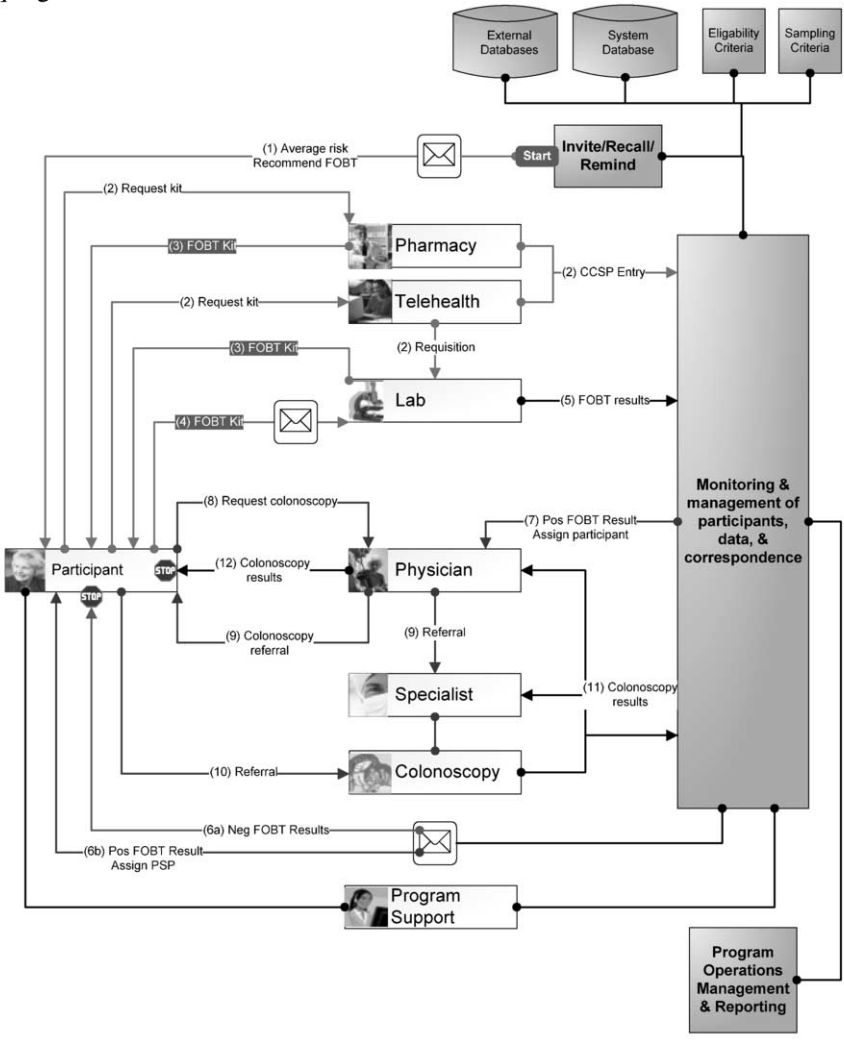


**Figure 1.** Example colorectal cancer screening program workflow scenario.

The jurisdiction-wide colorectal cancer screening program described is a unique initiative in Canada, as it will harness the expertise and potential involvement of many different stakeholders: family physicians, pharmacists, Telehealth, laboratories, specialists, hospitals/facilities, epidemiologists, public health officials, and finally, and most importantly, the individual participant. The success of the program will depend on the support and buy-in of these stakeholders. To improve success, the implementation and use of an information system that links this community of stakeholders should prove advantageous. This will require the information system to meet different needs and expectations, as well as accommodate likely infrastructure differences among the various information/data systems that need to be leveraged.

The key to the long-term success of a cancer screening program that integrates with an information system is flexibility and expandability. As such, the design of the prototype system ensures adaptability to evolving cancer screening program elements, logic, and rules. Although the current Ontario program will involve two risk states (average and increased), two screening tests (FOBT and colonoscopy) and associated rules, it is very likely that elements of the screening program will change over time as new tests and evidence become available. To ensure a proactive approach to changes based on lessons learned in practice, the solution to be implemented would include a generic and configurable rules engine solution to facilitate additional configurations.

The design of the system also facilitates expansion to include other potential future screening programs (e.g., cervical cancer, prostate cancer). Thus, the initial application specific for colorectal cancer screening would be expandable in a broader Cancer Screening Programs Information System. The proposed design work flow for this screening program informatics system enables the addition and configuration of other screening program modules.

The system is designed to accommodate advanced analytics and higher-level business intelligence, e.g., GIS and aberration detection. With any new health solution that includes the individual as a user, the solution designer should anticipate that the information system should become a public health resource with high leveragability, contributing to evidence-based health care delivery. Health information systems are often developed and implemented with little to no thought given to added-value beyond the immediate core functionality. Evidence-based decision-making requires not only access to appropriate data, but also the functionality to enable the use of that data in supporting public health practice.

Throughout the functional design phase of this project, empowerment of the at-risk individual with access to personalized information and support was the core consideration. The leveraging of existing health records to facilitate risk profiling and the proactive engagement and education of individuals with personalized information were considered key functional requirements of the system. In addition, the system must provide participants with easy web-enabled access to view their status in the cancer screening program, including access to testing results. The system should also provide on-line resources to facilitate scheduling of activities, updating of personal profiles, and access to additional relevant information.

## 3. Cancer screening program information system – Infrastructure and functional architecture conceptual design

In designing the cancer screening information system, existing technologies were leveraged to provide the ability to manage patient demographics, provider information, and clinical information; and facilitate integration of rule-based notification and reminder and recall components. In addition, the system must support electronic links from laboratories, electronic medical records (EMRs), and hospital information systems.

Key application components, such as system administration (including security and auditing), enterprise Mater Patient Index (MPI), Messaging System (MS), and Vocabulary Service (VS), were adopted from COTS (commercial off-the-shelf), MOTS (modifiable off-the-shelf) and GOTS (government off-the-shelf) tools. The conceptual infrastructure and functional architecture of the information system is depicted in Figures 2 and 3.

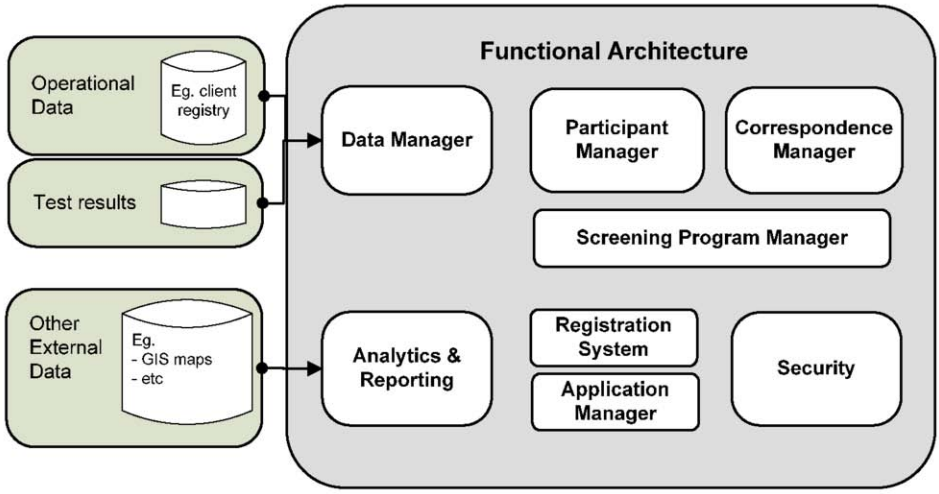


**Figure 2.** Cancer screening information system functional architecture.

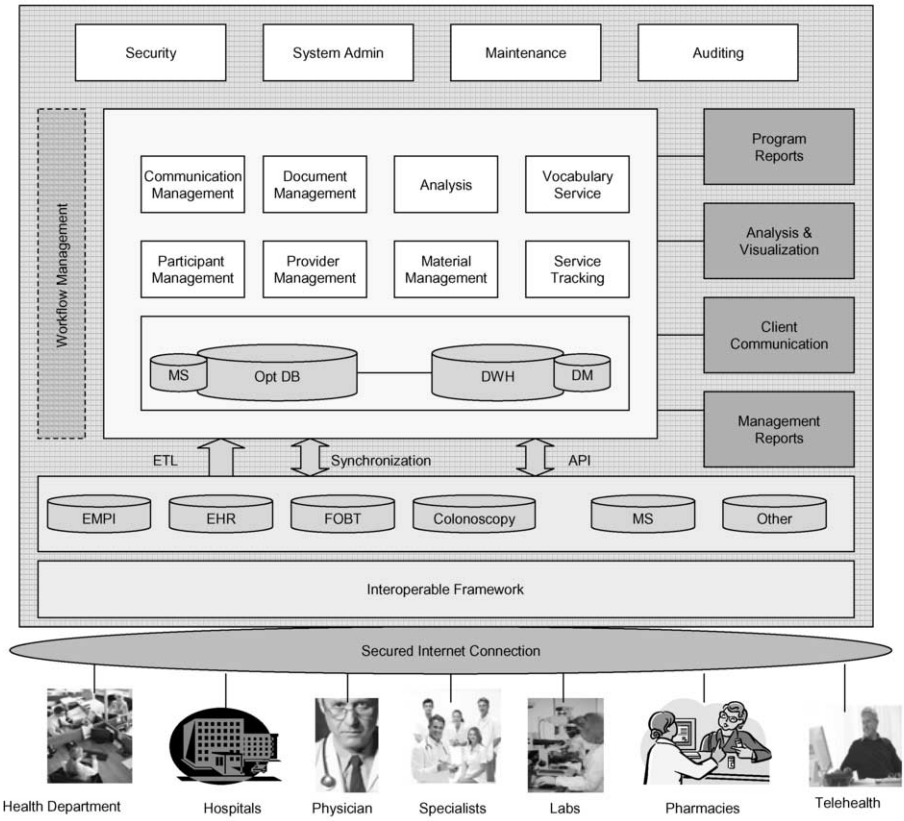


**Figure 3.** Cancer screening information system architecture overview.

Core function elements and considerations of the solution include the following: Data Management (accessing and administering multiple data sources including electronic health records, test/procedure results, messaging databases, and others); Participant Management (assigning risk profiles and FOBT and colonoscopy frequency, providing users the ability to view participant status); Correspondence Management (generating and delivering invitation and reminder messages, together with test/procedure results to the participant); Screening Program Management (specifying program workflow and business rules for one or more cancer screening programs); Analysis (providing visualization, analysis, and evaluation resources including GIS, charting, graphing, and trending tools) and Reporting (enabling the generation of add hoc and routine reports); and Registration System (registering participants into the program, and assigning user roles). Lastly, as the cancer screening system will collect individual health data, Security and Privacy considerations are key. The information system was designed with secure data transmission and storing processes to ensure the required privacy of the information. Hence, the enforcement of a security standard is necessary in authentication, table and data-filed level access control, and auditing.

Given that it is envisioned that the cancer screening system will need to integrate into a jurisdiction's broader e-health framework, the solution has been designed to leverage the host organization's supporting applications and infrastructure. Technical

considerations have been incorporated into the design of a number of the system elements including patient management, provider management, material management, service management, communication management, document management, and vocabulary services. The application framework needs to adhere to the host information technology standard and deployment practices, which can be portable across applications. Proper data sharing and interfacing mechanisms depend on the interoperability framework and data standards. With the development of various international clinical vocabularies and health messaging, the cancer screening program can leverage the work of other public health organizations standards (e.g., ICD, SNOMED, LOINC and HL7) and consolidate management and maintenance of data exchange amongst different systems.

## 4. Conclusions

Although it is well accepted that organized population-based cancer screening programs can effectively reduce mortality, little effort has been invested in designing, developing, and implementing information systems to support these programs. Common cancer screening programs do not leverage technology and do not include the patient in the process. The system as designed herein facilitates the sharing and management of information among the many stakeholders. Most importantly, the system is designed to proactively engage and retain participants.

Empowerment of the at-risk individual is the core business requirement. Ultimately, individuals decide on their own whether or not they wish to be involved in a cancer screening program. The hope is that by proactively engaging individuals, providing them with personalized information, and facilitating their involvement in the cancer screening program with easy-to-use information management tools, the likelihood of program enrollment and participation will be greatly increased.

## References

[1] National Cancer Institute of Canada, http://www.ncic.cancer.ca
[2] American Cancer Society, http://www.cancer.org
[3] Center for Disease Control, http://www.cdc.gov

# Aspects of Electronic Health Records

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# Computer Generated Operation Notes

VA CURRALL MRCS[1] and TJ CHESSER FRCS (Orth)
*Department of Trauma and Orthopaedics, Frenchay Hospital, Bristol, UK.*

**Abstract.** Providing an appropriate operation note is not only good practice, it is a professional and legal requirement. It was therefore necessary to ascertain whether operation notes generated by a clinical information system were of acceptable quality compared to handwritten notes when the Bluespier Patient Manager, a clinical information system, was introduced into an orthopaedic trauma unit. A four week prospective audit of operation notes was conducted both before and after its introduction, with standards based on criteria from the Royal College of Surgeons of England, plus additional orthopaedic criteria. 119 operation notes were reviewed before the introduction of computer-generated notes and 137 notes afterwards. Computer- generated notes were of better quality in all areas except the details of the author and time of generation. Previous audits of the quality of general surgical operation notes in district general hospitals have shown variable results and several solutions have previously been tried. With the advent of the National Programme for IT (NPfIT), computer generated notes are the next logical step. The introduction of computer-generated operation notes has improved their quality in terms of compliance with Royal College guidelines and other orthopaedic criteria.

**Keywords.** Computerised medical records systems; operative surgical procedures; orthopaedic procedures

## 1. Introduction

In the past, orthopaedic operation notes have been described as “untidy one-liners”[1]. Although this is probably a little harsh, providing an appropriate operation note is not only good practice[2], it is a professional[3] and legal requirement. The operation note should be legible, accompany the patient and have sufficient detail to enable continuity of care by other healthcare staff[2].

## 2. Method

The Bluespier Patient Manager (Bluespier International, Grafton Flyford, Worcestershire, United Kingdom) was introduced into an orthopaedic trauma unit. This clinical information system is used to store outpatient and ward round notes as Word files, track inpatients and manage the trauma board and operating list. Operation notes are also generated via proformas, which are converted into Word files, which are then checked, saved and printed by the author. Prior to this, operation notes were

[1] Corresponding author: Department of Trauma and Orthopaedics, Frenchay Hospital, Bristol, BS16 1LE, United Kingdom; E-mail: verity_currall@hotmail.com

handwritten on paper with only basic prompts (patient details, procedure and indication).

A four week prospective audit of all operation notes was conducted both before and after the introduction of Bluespier. Its use for operation notes was not compulsory, but was strongly encouraged. The audit standards were based on criteria set out by the Royal College of Surgeons of England[2], as well as additional orthopaedic criteria, based partly on British Orthopaedic Association guidelines[4,5] (Table 1).

**Table 1**: Criteria for assessment of operation notes. DOB = date of birth; DVT = deep vein thrombosis

| **Royal College of Surgeons Criteria** | **Additional Orthopaedic Criteria** |
|---|---|
| Patient name, number, DOB | Position |
| Date and time | Tourniquet time and pressure |
| Operating surgeon and assistant | Local anaesthetic |
| Consultant | DVT prophylaxis |
| Diagnosis | Post op antibiotics |
| Procedure title | Check x-ray |
| Incision | Weightbearing/mobilisation |
| Operative findings | Removal of sutures |
| Procedure details | Outpatient appointment |
| Prostheses | |
| Closure/sutures | |
| Immediate post-op instructions | |
| Surgeon's signature | |

Clearly, not all criteria would be applicable to every procedure (e.g. prostheses). The use of a tourniquet and/or local anaesthetic was cross-checked with the nursing record.

## 3. Results

One hundred and nineteen operation notes were reviewed before the introduction of computer-generated notes and 137 notes afterwards. Of these, 116 (85%) were generated via computer and 21 (15%) were handwritten.

In the notes from before the introduction of Bluespier, the criteria were generally met, but the documentation of tourniquet (pressure 17/33 = 52%; time 24/33 = 73%) and local anaesthetic (14/24 = 58%) use intraoperatively were poor. This was also the case for postoperative instructions, including check x-ray (67/85 = 79%), outpatient appointment (73/97 = 75%), suture removal (60/81 = 74%) and postoperative antibiotics (35/78 = 45%).

From a graphical comparison between the two sets of results (Figure 1), it can be seen that there were large differences in some of the criteria. For these criteria, the post-Bluespier notes results were also divided into those operation notes generated using the computer and those which were still handwritten and the comparisons are summarised in Table 2.

**Figure 1**: Comparison between pre- and post-Bluespier results. DOB = date of birth; OPA = outpatient appointment; Local = local anaesthetic; ROS = removal of sutures

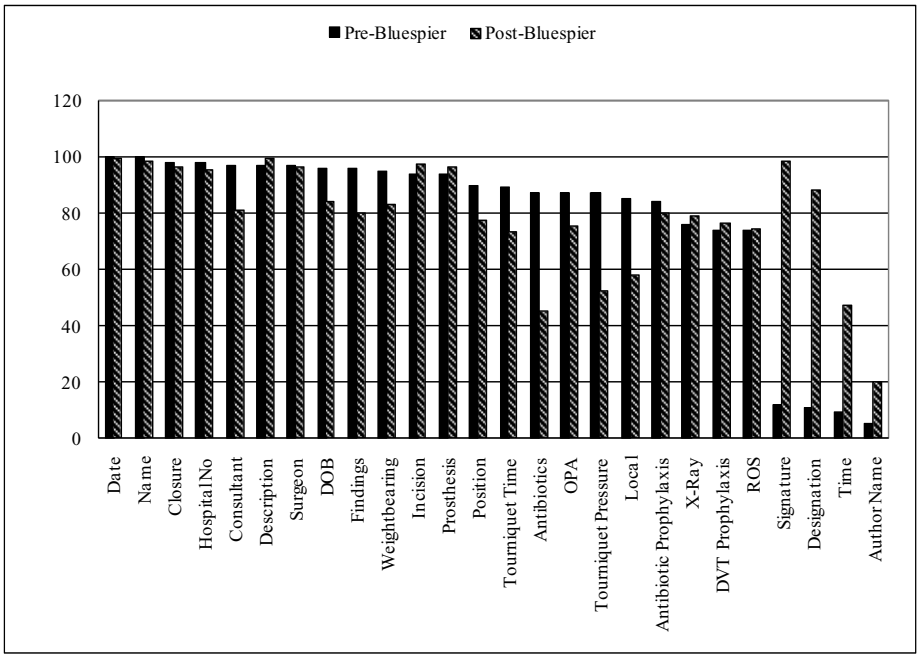


**Table 2**: Summary of differences between quality of operation notes, from pre- and post-Bluespier notes, both written and computer-generated. DOB = date of birth; OPA = outpatient appointment.

| % | Pre Bluespier | Total | Post Bluespier Bluespier | Written |
|---|---|---|---|---|
| Consultant | 81 | 97 | 100 | 81 |
| DOB | 84 | 96 | 100 | 76 |
| Description | 99 | 97 | 99 | 86 |
| Findings | 80 | 96 | 98 | 81 |
| Prosthesis | 96 | 94 | 97 | 70 |
| Position | 77 | 90 | 92 | 79 |
| Local anaesthetic | 58 | 85 | 85 | 86 |
| Tourniquet time | 73 | 89 | 90 | 83 |
| Tourniquet pressure | 52 | 87 | 86 | 100 |
| Tourniquet not mentioned | 24 | 9 | 10 | 0 |
| Weightbearing status | 83 | 95 | 96 | 88 |
| Prophylactic antibiotics | 45 | 87 | 95 | 55 |
| OPA | 75 | 87 | 91 | 65 |
| X-ray | 79 | 76 | 78 | 65 |
| Signature | 98 | 12 | 0 | 76 |
| Designation | 88 | 11 | 0 | 71 |
| Author Name | 20 | 5 | 0 | 33 |
| Time | 47 | 9 | 0 | 57 |

Of the criteria where the post-computer notes scored more highly than the pre-computer notes, most (including general details, operative details and post-operative instructions) did so because the computer-generated notes were of a higher quality. The post-Bluespier written notes had similar scores to the pre-Bluespier notes.

There were, however, a few exceptions. The documentation of local anaesthetic and tourniquet use was much better in the post-Bluespier notes, but this improvement took place in both the computer-generated and written notes. There is no obvious explanation for this, although both criteria scored particularly badly before the introduction of computer-generated notes.

The only areas in which the computer-generated notes were worse than the handwritten notes were in the details of the author (name, designation and signature) and time of generation, none of which are routinely contained in the computer-generated notes. With the exception of the signature, however, the other details are available from a separate audit trail function of the system.

## 4. Discussion

Previous audits of the quality of general surgical operation notes in district general hospitals have shown variable results [6,7]. Several solutions to the problem have previously been tried. The use of an aide-memoire in theatre has improved the quality of notes in ENT departments, in terms of patient details and abbreviations [8], as well as adherence to Royal College guidelines [9]. The introduction of a proforma in trauma and orthopaedic surgery significantly improved the documentation of several criteria, including patient number, consultant, diagnosis, position and the use of tourniquets and antibiotics [10].

With the advent of the National Programme for IT (NPfIT), computer generated notes are the next logical step. A computerised template with drop-down menus and free text proved better than handwritten notes in ENT emergency clinics [11]. An early database management system for general surgery was effective in collecting data and allowed the generation of operation notes, but their quality was not investigated [12]. In another study, operation notes produced by word processor using predesigned templates scored more highly than written notes using a proforma [13].

Our results show that the quality of the operation notes in most criteria improved after the introduction of a computer-generated operation note as part of the Bluespier clinical information system. Apart from the documentation of local anaesthetic and tourniquet use, the quality of written notes had not improved over the same period, so it is reasonable to attribute the change to the use of computer-generated operation notes. The main deficiency was the lack of signature on the final printed operation note, but should be easy to remedy with education or the use of electronic signatures.

Although ease and speed of use were not specifically investigated in this study, the general impression of the users was that the system is easy to use, although some of the proformas need minor alterations. It initially takes a few minutes more to produce a computer-generated note than a written one, but this decreases with familiarity and the use of personal default settings. There are also considerable time savings when needing to check an operation note if the paper notes are not readily available (for example, when a patient is readmitted or the notes have been lost before an outpatient appointment). In addition, audit and log book generation is easily achievable.

The NHS Care Records Service (CRS) will take several years to introduce, but will eventually allow clinicians to access linked records from every NHS organisation used by a patient (from both primary and secondary care), with details of all investigations and treatment, including operation records [14]. The Bluespier system achieves this in terms of operation notes, as well as ward round and outpatient notes. Development will soon allow interface with PACS and laboratory investigations to allow a fully integrated system.

In conclusion, the introduction of computer-generated operation notes has improved their quality in terms of compliance with Royal College guidelines and other orthopaedic criteria.

## References


[1] Campling EA, Devlin HB, Hoile RW and Lunn JN. The report of the national enquiry into perioperative deaths 1990; 131-4

[2] The Royal College of Surgeons of England. *Good Surgical Practice*. London: The Royal College of Surgeons of England, 2002

[3] General Medical Council. *Good Medical Practice.* London: General Medical Council, 2006 [4] British Orthopaedic Association. *Knee Replacement - a Guide to Good Practice*. London: British Orthopaedic Association, British Association for Surgery of the Knee, 1999

[5] British Orthopaedic Association. *Primary Total Hip Replacement: A Guide to Good Practice*. London: British Orthopaedic Association, 2006

[6] Baigrie RJ, Dowling BL, Birch D and Dehn TCB. An audit of the quality of operation notes in two district general hospitals: are we following Royal College guidelines? *Ann R Coll Surg Eng* (Suppl) 1994; **76**: 8-10

[7] Mathew J, Baylis C, Saklani AP and Al-Dabbagh AR. Quality of operative notes in a district general hospital: a time for change? *The Internet Journal of Surgery* 2003; **5(1)** http://www.ispub.com/ostia/index.php?xmlFilePath=journals/ijs/vol5n1/record.xml

[8] Bateman ND, Carney AS and Gibbin KP. An audit of the quality of operation notes in an otolaryngology unit. *J R Coll Surg Edinb* 1999; **44**: 94-5

[9] Shayah A, Agada FO, Gunasekaran S, Jassar P and England RJA. The quality of operative note taking: an audit using the Royal College of Surgeons Guidelines as the gold standard. *Int J Clin Pract* 2007; **61(4):** 677-9

[10] Al Hussainy H, Ali F, Jones S, McGregor-Riley JC and Sukumar S. Improving the standard of operation notes in orthopaedic and trauma surgery: the value of a proforma. *Injury* 2004; **35**: 1102-6 [11] Hobson JC, Khemani S and Singh A. Prospective audit of the quality of ENT emergency clinic notes before and after introduction of a computerized template. *Journal of Laryngology & Otology* 2005; **119**: 264-6

[12] Dale RF and Midwinter MJ. Use of database management system by surgeons to produce operation notes. *Ann R Coll Surg Eng* (Suppl) 1996; **78**: 272-5

[13] O'Bichere A and Sellu D. The quality of operation notes: can simple word processors help? *Ann R Coll Surg Eng* (Suppl) 1997; **79(5):** 204-8

[14] NHS Connecting for Health. *Guidance for the NHS about Accessing Patient Information in New and Different Ways and What this Means for Patient Confidentiality*. London: NHS Connecting for Health, 2006

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# Personals Attitudes towards Robot Assisted Health Care – a pilot study in 111 respondents

Ola Göransson, BS[1], Krister Pettersson, BS[1], Pär A Larsson, PhD[1,4], Bo Lennernäs, MD, PhD[2,3]
*1 Fyrbodal Research Institute, Uddevalla,*
*2 Sahlgrenska Academy, Dept of Oncology, University of Gothenburg,*
*3 iRobis Vasaplatsen 2, 41134 Gothenburg,*
*4 Sahlgrenska Academy, Dept of Neuroscience and Physiology, University of Gothenburg,*
*All Sweden.*
*O. Göransson and K. Pettersson. have equally contributed in this study.*

**Abstract**
**Background**: The aim of this survey was to examine health care professional's attitudes towards technology involving support from artificial intelligence (AI), robots and humanoids. Within 10-15 years, every third student has to choose occupation within the health care sector to obtain the current personal level, due to the aging population and retirement within the health service sector.
**Material & Methods**: The preliminary investigation interviews presented a wide range of activities. These were nursing tasks, service tasks, monitoring/alarms, telemedicine and social communication. First, a five minutes presentation movie was presented. The movie demonstrated expected personal needs in the future and what robots and AI can do today and tomorrow. After this presentation, the 111 respondents, from different representative care institutions, replied on a questionnaire that dealt with selected areas identified above. The questions included different views of robots as supported aids in healthcare.
**Results & Discussion**: The respondents were overall negative using AI and robot technology related to caring activities. However, all groups were positive in using robots in service tasks, monitoring/alarms, telemedicine and social communication. Of 29 assertions, 18 were mostly positive and 13 of them were over 70 % positive. The frequency of positive and negative attitudes, were similar in the central areas. Within the caring area, a positive robot assisted task requires an interaction (collaboration): caregiver-robot-individual and subsequently, within the nursing area; robot assisted tasks must involve a certain degree of human caring.

## 1. Introduction

The aging population in Europe, Asia and US is a challenge for the health care system (1, 2). Problems are, first, that the number of patients will increase due to large age groups after World War II and, second, the healthcare sector will loose labour due pension attrition and, third, the middle age is increasing (3).

In Sweden it has been calculated that in 2020 more than 30% of the healthcare staff will be missing if the share of students at secondary school remains at its current

level. However, one problem is that relatively few students are (at least in Sweden) interested in the health care as a future base area for their carrier (3).

Can robots in health care be a part of the solution that is urgently needed? First, we have to define the words robot, humanoids and artificial intelligence (AI). The word Robot first appeared in the play R.U.R (Rossum's Universe Robots), by Karel Capek (Czechoslovakia), published in 1920, and the word robot is derived from the Check noun robota which means labour. Furthermore; humanoids are robots that behave, interact with and look like humans.

AI can be divided into several sub-groups. For example; artificial intelligence Neural Networks is one way to train a system based on a certain data set (4) and genetic programming (5) is a path inspired by biological evolution to find computer programs that perform a user-defined task. In this work, robot is a machine that uses AI is any form to behave and interact with humans.

Asia, in particular, is more robot-friendly then the "old world". For example, scientists in Korea have stated that in 2013 they will have a full working health care robot (6). There are several publications related to the subject (7-9) and the use of artificial intelligence in the healthcare sector.

In the present pilot study the aim was to evaluate the attitudes towards robot assisted health care services in Sweden. Different sectors and staff settings of healthcare were investigated in respect to possible areas of robot-implementation.

## 2. Material & Methods

Initially three sectors of health care valid for robot implementation were identified (clinical work at hospital, caring/nursing at the countryside and in the city). Interviews with heads of five departments was conducted which resulted in a number of activities possible for robot implementation. These were nursing/caring tasks (NC), service tasks (ST), monitoring/alarms (MA), telemedicine (T) and social communication (SC). A questionnaire of total 29 items (with the possibility to add comments) and a five minutes long information movie showing the technical status were produced. The presentation included different views of robots as aids in health care (6 NC, 8 ST, 3 MA, 5 T and 7 SC). The alternatives were: "not at all", "less", "well", "very well" and "don't know" (dichotomised 1,2,3,4 and 0 respectively). The intention of the movie was to indicate the personal needs in the future, what robots and artificial intelligence may do future and initiate the question if robots can be used in future health care. In total 111 respondents at five different health care departments responded to the questionnaire after a short introduction including the presentation movie. In the analysis attitudes were registered in each of the activities groups. The groups were; gender, age, years at work, different departments and position.

## 3. Results

Of the 29 assertions, 18 were identified as positive and 13 of them were over 70 % positive in using a robot at their department. All groups were positive in using robots in nursing activities, MA, T and SC. In the ST group 2/ 8 responds were negative, and these contain a certain amount of caring (Figure 2). The respondents were overall negative using AI and robot technology related to caring activities (66%) except when

the tasks contained a big portion of nursing and/or the humanoid is not acting alone (Figure 1). The frequency of positive and negative attitudes, were similar in the central activities and there were no clear divergence between different groups of respondents and type of work place.

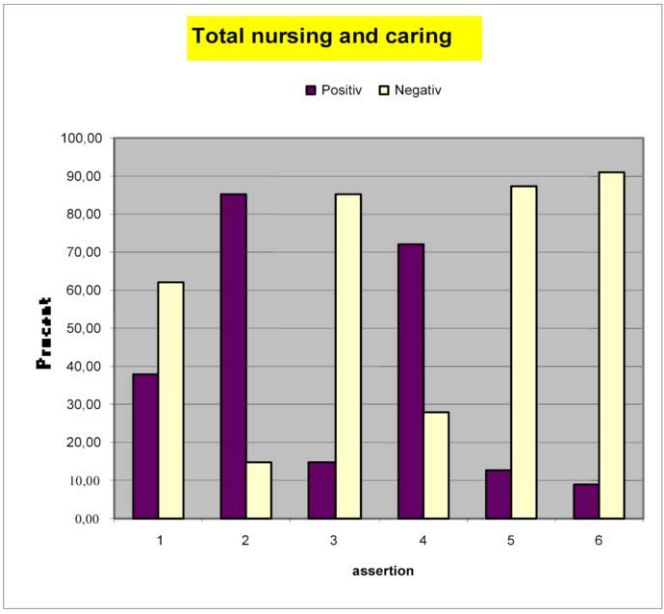


Figure 1

The Figure shows the frequency of positive (dark) and negative (light) of six questions concerning nursing and caring tasks.

The questions were:

1. you can have a humanoid helping you care for a patient.
2. a humanoid can be a good help for persons with agile defects or amputation.
3. a humanoid can feed the patient.
4. a humanoid can carry out certain monotonous movements during physiotherapy or assist you with the training.
5. a humanoid can perform “kroppsnära” tasks.
6. a humanoid can be at aid with the hygiene for the patient.

As show below assertions 2 and 4 has more positive responds and that is because the assertions contains a big portion of nursing and/or the humanoid is not acting alone.

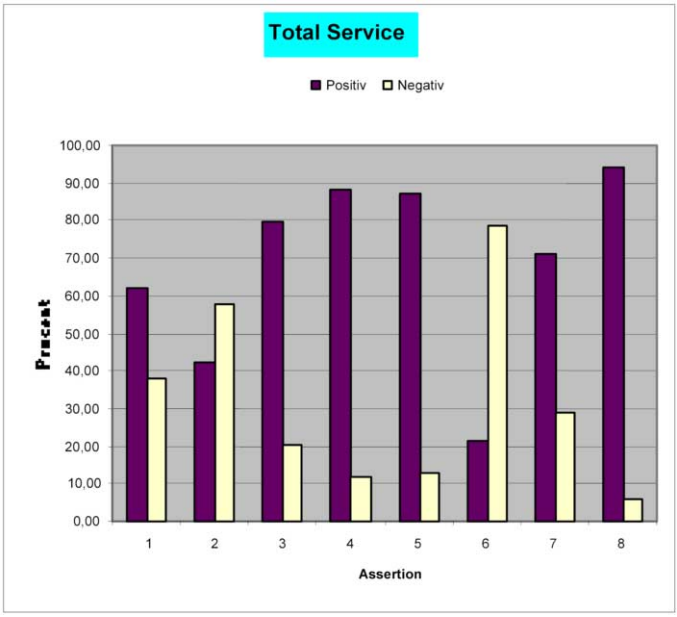


Figure 2

The Figure shows the frequency of positive (dark) and negative (light) of eight questions concerning service tasks

The questions were:

1. this technology can handle bed transportation.
2. the technology can be a support for decision-making.
3. a humanoid can fetch and leave stuff for the patient on the ward or at home.
4. the technology can be a support for the patient's memory.
5. the technology can remind the patient to eat and even heat a meal for her.
6. medicine distribution can be done by a humanoid.
7. the technology is suitable for more risky tasks in e.g. x-ray, radiation treatment or cytotoxin treatment.
8. a humanoid can do the cleaning.

As show below the negative answers in assertions 2 and 6 contains a lot of caring and therefore get a negative response.

## 4. Discussion

The aging population in Europe, Asia and US is a challenge for the future health care. In this study we have investigated health care personals attitudes to robot assisted health care and the result indicates a positive attitude to the potential use of robots in nursing, MA, T and SC.

The Royal Society has stated that information and communication technologies (ICT) have the potential to transform radically the healthcare system. They address some future ICT-health challenges and recommendations ranging from technology evaluation, development, education and government funding (10). Several institutes and key persons have high-lighted that the development of robots / humanoids will ha a

large impact on our society in the future, and that the industry and the market will be large and the one of the most important future economies (11).

The knowledge about attitudes to robots in health care, are today very limited in Sweden. Health care personals attitudes to technology with AI are multifaceted. It can't be simplified to that extend attitudes relates totally to an activity. Even if there are strong tendencies in that direction every single work task must be examined by itself. Further studies are needed. Especially patient's relative's attitudes must be studied.

A part of the solution, to the problem with future lack of personal, will most certainly be technical whether we want it or not. If this technology should be accepted and used by the users it is our definite opinion that they must be involved in the development, they are the experts of where and how it can be used. This statement is also in accordance with the Royal Society, which stated that the single most important factor for ICT implementation is involvement of the user in all stages of the development. This study intends to be the first step towards a user centred development.

The result of the study was somewhat astonishing since attitudes were surprisingly positive. The staffs were in fact more positive than the head of their departments, but no group were positive in using robots near the patient. However, in some situations, such as assisting a nurse in caring was accepted.

The next step is to investigate attitudes among patients and relatives, but also to evaluate, in more detail, one or two areas of implementation, such as the development of a robot in the treatment room at a radiotherapy unit.

## 5. References

[1] OECD Observer No. 239, September 2003.
[2] Global Population Ageing, Migration and European External Policies. Malmberg B. Institute for Futures Studies. Nov 2006.
[3] Trends and Forecasts 2002. Statistics Sweden. www.scb.se.
[4] The effectiveness of artificial neural networks in evaluating treatment plans for patients requiring external beam radiotherapy. Lennernäs B, Sandberg D, Albertsson P, Silén A, Isacsson U. Oncol Rep. 2004 Nov;12(5):1065-70.
[5] Genetic Programming : An Introduction : On the Automatic Evolution of Computer Programs and Its Applications, P. Nordin, W. Banzhaf, R.E. Keller and F.D. Francone. Morgan Kaufmann Publication inc. 1998.
[6] Korean scientist group declare a fully functional robot in 2013 (http://www.korea.net/News/Issues/issueDetailView.asp?board_no=14110.
[7] Incorporating guidelines for health assistance inte a socially intelligent robot. Looije R, Cnossen F. Neerincx MA. 15Th IEEE international symposium on robot and human Interactive communication. Hatfield. Sept 6-8, 2006
[8] Meeting the challenges--the role of medical informatics in an ageing society. S Kock. Stud Health Technol Inform. 2006;124:25-31
[9] Robot who care for people. T Carroll. Servo 7;79-:2006
[10] Digital healthcare:the impact of information and communication tachnologies on health and healthcare. The Royal Society, 2006.
[11] A Robot in every home. Gates B. Scientific American. Jan. 2007.

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# Giving patients secure « google-like » access to their medical record

Catherine QUANTIN [a], Maniane FASSA[a], Gouenou COATRIEUX[b], Vincent BRETON [c], Jean Yves BOIRE[d], François André ALLAERT[e]
*a. Dpt. of Biostatistics & Medical Informatics, Inserm U866, CHU de Dijon*
*b. Inserm U650, LaTIM; GET ENST Bretagne, Dpt. ITI*
*c. LPC, UMR CNRS-IN2P3 Université Blaise Pascal, Clermont Ferrand*
*d. ERIM-ERI 14 INSERM, Faculté de Médecine, Clermont Ferrand*
*e. Ceren Esc Dijon & Department of Public Health, McGill University, Montreal, Canada*

**Abstract:** The main problem for the patient who wants to have access to all of the information about his health is that this information is very often spread over many medical records. Therefore, it would be convenient for the patient, after being identified and authenticated, to use a kind of specific medical search engine as one part of the solution to this main problem. The principal objective is for the patient to have access to his or her medical information at anytime and wherever it has been stored. This proposal for secure "Google Like" access requires the addition of different conditions: very strict identity checks using cryptographic techniques such as those planned for the electronic signature, which will not only ensure authentication of the patient and integrity of the file, but also protection of the confidentiality and access follow-up. The electronic medical record must also be electronically signed by the practitioner in order to provide evidence that he has given his agreement and accepted responsibility for the content. This electronic signature also prevents any kind of post-transmission falsification. New advances in technology make it possible to envisage access to medical records anywhere and anytime, thanks to Grid and watermarking methodologies.

**Keywords**: data security, electronic signature, direct access, medical record, patient identifier, watermarking, grid

## Introduction

Throughout Europe, patients are entitled to have direct access to their medical records and this has been true, even in France where previously only indirect access via a physician was allowed, since 4 March 2002. At present, the simplest solution is to give patients a copy of their paper medical record or, if it has been computerised, to give them a printed record or even a copy on a machine readable storage medium. This arrangement of the communication process can be carried out “without constraint at reasonable intervals and without excessive delay or expense” as required by article 12 of the Directive “On the Protection of Individuals with regard to the Processing of Personal Data and on the Free Movement of Such Data” [1]. The time taken to grant access provides the opportunity to ensure that the identity of the individual making the request can be properly authenticated and that any additional conditions on access, such as those provided for in article 13 section 1(g) “for the protection of the Data Subject or

the rights and freedoms of others" have been correctly observed. This current approach does not involve any particular risk to the information system, but there are already pressing demands from patients with their increasingly powerful computing facilities to speed up these processes, and to have direct access to medical record systems. These pressures will be difficult to resist in the present, fast moving, electronic environment and it is difficult to imagine that the traditional, delayed, process will be accepted for much longer. Soon, patients will be expecting to have direct access to their medical files via the internet or its equivalent. Instead of trying to resist this inescapable evolution, it is preferable to seek solutions that provide safety for both patients and medical record systems while allowing this valuable development in the area of personal freedom and human rights.

The French project to implement personal medical records called DMP for each patient and accessible to the patient has raised many difficulties such as defining a common identifier for all health care purposes and structures and centralizing storage of all records. The French health authorities are today redefining the scope of their project taking into account the results of the first experimentation in day-to-day practice. The proposed solution of "google-like" management (providing patients with permanent access to their medical information wherever it has been stored) is an alternative to centralised storage but needs a very high level of security. This paper sets out to define steps in the process of creating a system, similar to a search engine, that will provide patients with secure access to their medical records.

## 1. Proposal for Secure « Google Like » Access

Today, the main problem for the patient who wants to have full access to his or her health information is that this information is very often spread over many medical records kept by different health structures or professionals that even the patient doesn't remember anymore. Therefore, it would be convenient for the patient, and for his medical practitioner, after being identified and authenticated, to use a kind of specific medical search engine to gain access to the medical information of the patient wherever it has been stored. To provide this access, there are many possibilities. Our proposal relies on two procedures. In the first, the patient authorizes his/her medical practitioner to have access to his/her medical information. As happened in France for the Personal Medical Record (DMP) project, the issue of access to sensitive information (such as HIV, psychiatric diseases, sexual abuses) may be raised. In the second, the patient has direct access to his/her medical data and selects the information that he wants to communicate to his medical practitioner, so that there is no need for the patient to ask for sensitive information to be masked.

In a utopian world, access could be linked to a procedure ideally using a digital signature provided by a patient's medical smart card. More basically, it could be sufficient to incorporate in this secure "google-like" access, the same process of security that has been incorporated in our credit card and that we use daily when we want to have access to our bank account or withdraw money. The main difference with the banking system will be the need for card and access management in order to make it impossible for healthcare information networks to be organised in such a way that the patient is obliged to stay in the network if he wants to keep his "on line" access to his medical record. This risk does not exist in countries where medicine is managed

exclusively by public organisations, but information management may be an important issue when different private healthcare providers compete.

## 2. Conditions of implementation

### *2.1. Authentication of patients and health professionals before access to medical records on line*

Direct access to medical files via electronic media gives rise to many difficulties, and hence very strict access control and authentication measures are essential. The principal difficulty in this field is to ensure that only the holder of the access rights will be able to gain access to the Personal Data. Access control for patients is considerably more complex than for health professionals. For example, in hospitals, the management can encourage administrative and medical staff to participate in relevant training courses. In contrast, patients would have to be provided with intuitive, foolproof access facilities, without requiring them to participate in any training courses. The difference between facilities designed for "doctor or nurse" access and facilities designed for "patient or general public" access is substantial even though the number of applications and functions available to the patient would, of course, be far smaller than that available to and required by members of staff.

A brief consideration of the risks associated with unlawful access to Medical Record systems for patients and the healthcare organization makes it clear that a very reliable authentication system will be required before allowing any public access to such systems. The traditional approach for the authentication of individuals has two components: assertion of identity, followed by proof of the identity [1]. Generally, this proof can be in terms of something that the individual knows or something that the individual has or something that the individual is. Technical solutions are available to cover any degree of proof in authenticating individuals, but many of them would require the establishment of a substantial organization before they could become effective.

Biometric technologies are sometimes proposed as a way to associate a patient with his or her medical data, as they do not require the patient to bring any documents or remember any information. Though this technology represents real progress both in the identification and in the authentication of the patient, there are still many questions [2] regarding the accuracy and reliability of each biometric technology and the associated costs. But the main problem lies in the acceptability of such systems by organizations concerned with ethical considerations such as patients' associations, national ethics committees, human rights associations, and national committees for data protection. For example, in France, the use of biometric solutions for identification in the field of health has not been approved by the National Ethics Committee.

Even today, after extensive computerization of Medical Record systems, the simplest and most common authentication mechanism is still that of an "Identifier" together with a "Password". This approach combines simplicity of use and management, but it is the weakest and the most unsatisfactory mechanism [3]. The most satisfactory approach would lie in the creation of an individual chip card, including the electronic signature cryptographic algorithms [4], both for patients and health professionals. But this will take some time and will engender considerable expenditure before becoming the accepted standard. Moreover, due to the legal

recognition of the electronic signature, this partial solution would provide access follow-up, with legal value of proof in front of the courts. However, as this more satisfactory electronic solution cannot be implemented now and everywhere, only inferior less safe solutions can be considered. For example, the electronic signature has just been retained in France for the access of health care professionals, but due to technical aspects the implementation of this electronic signature has been scheduled for a period of 3 years (French decree on confidentiality dated May, 15th, 2007).

Meanwhile, a possible solution is a smart card [5-7], associated with the attribution of a secret PIN code with 8 characters, like that used in France for the DMP project. This solution would require hospitals to be equipped with powerful firewall-type data-processing devices to filter access. In such a system, the patient commonly declares the list of medical practitioners who are authorized to have permanent access to his medical data. The access rights given to the medical practitioners can be erased at any time by the patient. For other medical practitioners consulted by the patient, the patient authorizes temporary access.

In the case of an emergency, when the patient is unable to express his will, the easiest solution is to provide access through a specific procedure involving the responsibility of the medical practitioner in charge of the patient, with immediate notification to an official security supervisor. People may argue against this solution as even though the medical practitioner can be prosecuted in case of illegal access, security has been breached. This partial solution represents a compromise between security rules and the patient's health care and arises from the fact that collected data is made available. It is a general principle of penal law to consider that citizens generally act in accordance with social rules and that penalties are imposed as a deterrent and to punish those who break the law.

### *2.2. Verification of the data source*

#### *2.2.1. Regarding the patient*

Recently, watermarking has been proposed for the protection of medical information. Basically, watermarking is defined as the invisible embedding or insertion of a message in a host document, for example an image. Watermarking provides an original way to share a document with some ancillary data like protection data or meta-data. For example, with regard to images, watermarked data remains attached at the signal level independently of the image file format. It means that embedded data can be recovered after file format conversion.

Most of the work on watermarking for medical images has concerned the need to verify image integrity (embedding a digital signature of the image) or improve confidentiality [8], as it is often considered that embedding information makes it more difficult for unauthorized persons to gain access to this information. Watermarking appears to be complementary to other security mechanisms. It gives access to a kind of communication channel that is transparent to non-compliant systems, as it is not an extra header information addition, while compliant systems will be able to read embedded data.

In the considered framework, access to or sharing of an isolated medical document requires that the document can be identified. A watermarked authentication code may allow identification of the health professional who consulted the patient data for the purpose of traceability, or the identification of the patient him or herself. To go further,

if the embedded identity is rendered anonymous [9], then it is possible to gain access to and link information concerning the same patient without knowing his or her identity so as to guarantee both privacy and interoperability. These patient privacy issues may appear during the verification process, which is necessary to reduce the risk of errors when identifying documents in everyday practice or when sending a patient's Electronic Health Record. For example, the verifier may be able gain access to patient data without authorization. This method may also provide a solution to the problem of the identification of lost medical documents. Further research and development is necessary to extend watermarking methodology to text.

#### *2.2.2. Regarding the health practitioner*

The medical record transmitted to the patients must be electronically signed by the practitioner to be sure that he has given his agreement and that no unauthorized modifications have been made. Here also, the recognition of the legal value of the electronic signature permits controlled electronic transmission of the medical record to the patient. This electronic signature also makes it possible to ensure that any modifications of the medical record, for example, adding new medical information, are made by the medical practitioner.

### *2.3. Data accessibility*

Providing patients with “google-like” secure access to their medical records requires the information to be available for querying and retrieval. Google is able to query and search all data published on the Internet. But, it will be absolutely necessary to ensure the security of this Internet environment before storing any medical data. An alternative is provided by grid technology which allows distributed data to be stored securely. This data can be consulted and queried according to personal access rights. Grids are defined as a fully distributed, dynamically reconfigurable, scalable and autonomous infrastructure to provide location independent, pervasive, reliable, secure and efficient access to a coordinated set of services encapsulating and virtualising resource. Their relevance for managing medical information has been investigated within the framework of the HealthGrid initiative [10], [11],[12],[13],[14]. The use of grids overcomes the difficulties inherent in a centralized storage system, especially high cost and complexity. Grids also make it possible to store data where or very close to where they are produced. Through grid authentication, authorization and accounting, only duly authorized persons can gain access to data which are encrypted and made anonymous when they are transmitted [15].

### *2.4. Technology against ethics and law: the limits of liability.*

Even if grid methodology allows us to solve the most important part of the problem concerning secure access of the patient to his or her medical record by embedding a strong identification marker in the document through watermarking, two main dangers still exist. The first lies in the fact that this process of "automatic" access is not accompanied by any medical explanation and even more importantly, there will be no medical warning about the contents that the patient will read. It is by no means certain that providing patients with routine direct access to their medical records automatically extracted from the database is a very satisfactory solution from a medical point of view.

If the medical records contain information which may cause serious psychological distress (possibly leading to suicide), the hospital or the medical practitioner could be held responsible from a legal point of view or at least from an ethical or deontological point of view. Moreover, the contents of the medical record also need to be conscientiously reviewed (updated or validated) before being delivered to patients. In other cases, information contained in a medical record may refer to third persons, and divulging such information may be considered a breach of confidentiality. Once again, the hospital or the practitioner may be held legally responsible. Therefore, even though providing patients with automatic access to their medical records appears to be satisfactory from a technical and data-security point of view, it may not fulfil the quality requirements for the security of healthcare information. No transmission should be allowed without the consent of the medical practitioner who takes care of the patient, or his representative. As the practitioner is legally responsible, his formal agreement to the transmission is required, and the transmitted document should be electronically signed by him.

The second point lies in the use of the medical record by the patient. As patients are deemed to be responsible adults, we will not consider the eventual unexpected effects of the communication of their medical records to their insurance company or bank, which may have required it officially or unofficially. From a medical point of view, the main problem could come from modifications of the medical record by the patient himself to erase information that prevents him from obtaining certain advantages. If such modifications were possible, imagine what could happen if a patient erased the fact that he was epileptic in order to be allowed to drive a machine of some kind. Thus, it does not seem desirable to give direct access to the system that manages the files to everybody, even authenticated users. The original medical record, which is the means to bring evidence in case of litigation, should be protected from any kind of attempt to modify the information by unauthorised persons. It will then be preferable to envisage a request procedure for access, including the search for the file and the extraction of the communicable documents authorized by the law. This approach, in which a special access file is created, could happen much faster than the time delay allowed in some European countries (in the UK the authorities have 40 days to comply with a Subject's Access request, whereas in France, the delay is 8 days).

## Conclusion

Thanks to advances in technology it is now possible to envisage access to medical records via the Internet anywhere and anytime, thanks to Grid and watermarking methodologies. Electronic access will require very strict identity checks using cryptographic techniques such as those planned for the electronic signature, which will ensure the protection of confidentiality, the integrity of the files, the authentication of the applicant's identity and access follow-up. The electronic medical record must also be electronically signed by the practitioner in order to provide evidence that he has given his agreement and has accepted responsibility, and to prevent any kind of post-transmission falsification of the record. Currently, the idea that every citizen will have an electronic signature allowing him to have direct access to his medical records anywhere appears to be Utopian, but this is the implication of much of the work that is going on world-wide in e-Government, e-Health and e-Shopping. With regard to search engines, who could have imagined ten years ago that a system would be able to retrieve

everything you have ever published and list all of the people who have made a reference to it in a matter of seconds!

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## References

[1] Allaert FA, Le Teuff G, Quantin C. Law and standards faced to market rules in health information security. Stud Health Technol Inform, 2003; 95:125-9.
[2] Vaclav M, Zdenek R. Biometric authentication systems. A technical report. Retrieved April 15, 2006 from ecom-monitor.com web site: http://www.ecom-monitor.com/papers/biometricsTR2000.pdf
[3] Chao HM, Twu SH, Hsu CM. A patient-identity security mechanism for electronic medical records during transit and a rest. Medical Informatics and the Internet in Medicine. September 2005;30(3):227-240.
[4] Allaert FA, Le Teuff G, Quantin C, Barber B. The legal acknowledgement of the electronic signature : a key for a secure direct access of patients to heir computerised medical record. International Journal of Medical Informatics 2004;73:239-42.
[5] Roger France FH, De Clercq E, Bangels SM. Purposes of health identification cards in Belgium – EFMI, European Federation for Medical Informatics, IOS Press, 2005, Connecting Medical Informatics and Bio-Informatics.
[6] Pharow P, Blobel B. eHealth Competence Center, Regensburg, Germany. peter.pharow@ehealth-cc.de Benefits and weaknesses of health cards used in health information systems. Stud Health Technol Inform. 2006;124:320-5.
[7] Pharow P, Blobel B. Fraunhofer Institute for Integrated Circuits IIS, Erlangen, Germany. Security infrastructure requirements for electronic health cards communication. Stud Health Technol Inform. 2005;116:403-8.
[8] Coatrieux G., Lecornu L., Sankur B., Roux C. A Review of Image Watermarking Applications in Healthcare, IEEE-EMBC06, Sept. 2006, New York, USA.
[9] Quantin C, Cohen O, Riandey B, Allaert FA. Unique patient concept : a key choice for European epidemiology. International Journal of Medical Informatics, 2007;76:419-426.
[10] V. Breton, K. Dean and T. Solomonides, editors on behalf of the Healthgrid White Paper collaboration,"The Healthgrid White Paper", Proceedings of Healthgrid conference, Studies in Health Technology and Informatics, IOS Press, Vol 112, 2005.
[11] Vincent Breton, Kevin Dean, Tony Solomonides The Healthgrid White Paper, Studies in Health Technology and Informatics, Vol 112 (2005) 249-321
[12] Olive M, Rahmouni H, Solomonides T, Breton V, Legré Y, Blanquer I, Hernandez V. SHARE, from vision to road map: technical steps. Medinfo. 2007;12(Pt 2):1149-53.
[13] Bridging clinical information systems and grid middleware: a Medical Data Manager Montagnat J, Jouvenot D, Pera C, Frohner A, Kunszt P, Koblitz B, Santos N, Loomis C. Stud Health Technol Inform. 2006;120:14-24.
[14] Erberich SG, Silverstein JC, Chervenak A, Schuler R, Nelson MD, Kesselman C. Globus MEDICUS - federation of DICOM medical imaging devices into healthcare Grids. Stud Health Technol Inform. 2007;126:269-78.
[15] Mohammed Y, Sax U, Viezens F, Rienhoff O. Shortcomings of current grid middlewares regarding privacy in HealthGrids. Stud Health Technol Inform. 2007;126:322-9.

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# Improving outcomes with interoperable EHRs and secure global health information infrastructure [1]

Luis Kun[(1)], Gouenou Coatrieux[(2)], Catherine Quantin[(3)], Regis Beuscart[(4)], with consultations, and contributions from Robert Mathews [(5)]
*[(1)] IRM College - National Defense University, USA (KunL@ndu.edu)*
*[(2)] GET ENST Bretagne; Inserm U650, France (Gouenou.Coatrieux@enst-bretagne.fr)*
*[(3)] Department of Biostatistics and Medical Informatics. Dijon University Hospital, France (Catherine.Quantin@chu-dijon.fr)*
*[(4)] CERIM, Lille 2 University, France (Regis.Beuscart@univ-lille2.fr)*
*[(5)] University of Hawai'i, USA (mathews@hawaii.edu)*

**Abstract** One of the central pieces for healthcare and public health is information. Through the shared use of the Information Super Highway and the WWW, for example, elder patients can, and indeed are "visited, diagnosed, treated and managed" from their homes, with the help of telemedicine systems. These technologies also provide society with additional benefits within a global health perspective, with applications ranging from disease prevention and genetics to surveillance and epidemiologic studies. For example, discoveries relating to the prevention or curing of a disease in one part of the world should be "known" everywhere else instantaneously. During an emergency, individuals travelling the world should be able to access their healthcare records for proper care, anywhere. Individuals emigrating from a country to any other should be able to use their information "seamlessly" in terms of the "old" and "new" information systems, no matter where they are. The information contained in multiple systems, i.e., civilian, military forces, etc., should appear transparently among all. However, at this time, significant questions regarding privacy of health information, quality of the services delivered and in general, the information assurance, i.e., authenticity, confidentiality, integrity, availability, and non-repudiation persists. A common aspect to information protection and sharing is interoperability. The authors believe that this term is poorly understood and consequently its incorrect use generates immensely negative consequences. The question raised by the authors then is, what is "true interoperability"?

## 1. Introduction

The provision of institutionalized healthcare has historically centered on face-to-face patient contact and assessment. However, due to enormous changes in the care-giving landscape, with respect to such things as hospital/professional specializations, changing/new disease types, changing societal behaviors and assumable fiscal risks, are requiring the use of sophisticated across-the-board approaches to establishing,

[1] This paper reflects the discussion results of the min-symposia entitled "Improving outcomes with interoperable EHRs and secure global health information infrastructure" held during the Annual IEEE EMBS Conference, 2007,in Lyon, France

maintaining, and improving high quality public healthcare infrastructures. The shift from a face-to-face patient contact, assessment, and treatment model - to one that may involve no "physical" contact at all. For example, one trend that is occurring in the USA, the European Union, and Asia as well is the use of telemedicine for homecare of the elderly with chronic conditions, and managing the patient via the Internet. [2] These shifts have required the implementation of a new model, involving highly sophisticated tool sets that synergistically and complimentingly co-exist with a model that previously, and almost wholly, existed as human centered organisms.

This required transitions/migrations from a largely known and comfortable model - to a distributed, decentralized, web of practitioner and services organisms, is causing wholesale chaos globally, as intellectual strains associated to process related encounters vis-à-vis transitions/migrations to be achieved, are of a nature, type and scale that humankind has never before encountered. The challenge involves more than just growing pains. At the core, absent are intellectual processes, mechanics, and the operational constructs for holistic [see figure 2] integration of practices. Although well intentioned, in lieu of the aforementioned necessary core, programmatic efforts have spawned and flourished, which are largely inconsistent with the related objective to improve health outcomes in every instance, aided by interoperability. However, much as in the case of the 'holy grail,' interoperability today, remains an immensely desired and priceless artifact - in humankind's imagination.

## 2. Toward A Unifying Structure

Considerations to institute interoperability, could only be characterized collectively as an after-thought; as in the case of a homeowner, who installs hefty electrical appliances without due consideration to the overall condition of the electrical wiring, or adding an additional floor of living space without consideration to aspects of the foundation. Today, lacking the proper holistic orientation to pursue interoperability has become a supremely hazardous liability. Traditionally, the absence of proper orientation has given way to the launching of efforts that meander aimlessly, cause strategic time loss, duplication of efforts, siphoning of enormous sums of taxpayer funds, mounting of lost opportunity costs, astonishing failures in advancement of interoperability, and hindering the achievement of organizational goals, and mission objectives.

Failures in the pursuit of interoperability as mentioned above can generally be attributed to the inability for multi-disciplinary, inter-disciplinary thinking, which has historically qualified the quietly deceitful, yet, imposingly precipitous nature, surrounding this exceptional challenge. Universally, there has been an undervaluing of the level of comprehensive and broad mental acuity required by those involved in the pursuit. The type of mental acuity as described, demands that persons will be able to draw professional and intellectual comfort from having to dwell perpetually at the intersection of optimal situational awareness, comprehensive multidisciplinary and interdisciplinary knowledge (profound knowledge), working knowledge of tools, techniques, and opportunities among other things.

[2] Shea, Steven, et. al., "A Randomized Trial Comparing Telemedicine Case Management with Usual Care in Older, Ethnically Diverse, Medically Underserved Patients with Diabetes Mellitus," Journal of American Informatics Association, Vol. 13, 2006.

To the extent that there is emplaced demand to understand the true meaning of interoperability, and the overarching implications of such meaning to the universal desire to improve outcomes in healthcare, the implementation of a secure global health information infrastructure, and globally portable Electronic Health Records, (EHRs), this mini-symposium benefited from the experiences and insights of Prof. Dr. Robert Mathews. [3] The mini-symposia presentations began with an orientation to the future; one geared to righting modern day perspectives, and stimulating participants to examine the issue of interoperability in a holistic, and systemic manner. It is fitting to begin this summary with the same orientation.

## 3. Interoperability and the context

Prof. Dr. Robert Mathews pointed to three distinct problem areas at the mini-symposium, which cloud the prospect for success in interoperability efforts. The amalgamation of the three problem areas in his assessment, persistently and consistently obfuscates the staggering power and influence of the subject. The distinct problem areas as assessed are as follows: a) the definition of a system, [See fig. 1] b) mis-understanding in the meaning, and mis-use of the term "interoperability," [See fig 2.] and lastly, c) the make-up of "information systems," in relationship to interoperability. [See fig. 3].


Figure 1, Source: "Some Myths Regarding Interoperability," Robert Mathews, CSATI/OSIA - University of Hawai'i.

[3] Prof. Dr. Robert Mathews is the leading authority on the subject of interoperability and integration of large-scale, ultra complex and highly distributed information systems in the world. His pioneering analyses into 'behavior of complex systems,' 'system interconnections' and the 'systems approach' have spanned several decades and include civilian, economic, political, military, and intelligence systems among others. The intellectual explorations into this challenging area by Prof. Dr. Mathews' is now revealing previously unrecognized factors relating to the effective and efficient inter-operation of disparate systems.

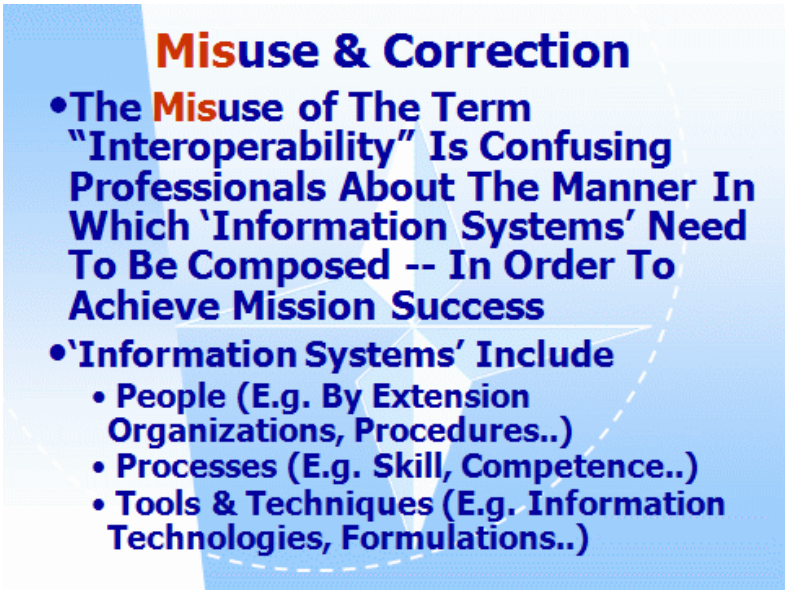


Figure 2, Source: "Some Myths Regarding Interoperability," Robert Mathews, CSATI/OSIA - University of Hawai'i.


Figure 3, Source: "Some Myths Regarding Interoperability," Robert Mathews, CSATI/OSIA - University of Hawai'i.

In detailing aspects of the thematic drivers, Prof. Dr. Mathews characterized the widespread difficulty in being able to understand the depth and scope of interoperability, as being allegorically symptomatic to someone suffering from an

occlusive cerebro-vascular condition such as hypo-perfusion, and the resulting inferior cerebral haemodynamical conditions. He says, "It is as though, there is great intellectual suffocation, or the permeation of a mental blindness, to being able to think critically about such a complex issue." In elaborating, he added that, "the ingrained desire and tendency of human kind - to reduce any complex landscape into that, which appears at least smaller, more simplified parts and, or abstractions, is a strong contributor to the problem."

Prof. Dr. Mathews says that our desire to understand such things as highly complex self-organizing systems, the human body, and interoperability are essentially at odds with humankind's natural tendency toward reductionism.

He states that "the human brain *desires, and leans* to facilitate such a reductionistic approach, allowing a mental blindness to manifest; inadvertently consenting to a 'process violation' to be perpetrated upon ourselves, and our analytical attention to be diminished, drawn by an instinctive leaning toward conveniences, to a subset of all there is." The result of such diminished thought process yields a product that is "less logical, less scientific, rational, efficient, effective, and least of all – reliable. Within those efforts designed to pursue interoperability, the intricacies and the highly delicate nature of working relationships among the multi-disciplinary and inter-disciplinary domains of systems and sub-systems in a highly complex ecosystem, Prof. Dr. Mathews says, are "least understood, or altogether ignored."

The summaries that follow represent independent bodies of work, and are examples of activities, which are to be considered as part of a more comprehensive orientation to improving global health outcomes. The summaries detailed are opinions of the respective authors, and should not be construed as holistic

## 4. Interoperability solutions in Hospital Information Systems (HIS) - Interoperability in Information Systems - An example: CPOE (Computer Prescription Order Entry)

**By Regis Beuscart**

In Hospital Information Systems (HIS), one of the main challenges involve the exchange of data between computerized applications. The interoperability of different professional applications with the administrative core of the HIS is necessary in order to ensure the usability and the efficacy of the whole system.

A HIS is developed around a core administrative system, gathering indispensable functions as:

- Patients information (administrative, medical, nursing)
- Administrative structure (organization of the hospital, hierarchical medical organization)
- Activities (Hospital Units, X-Rays, Biology, Operating Theatre, Consultations, Hospitalizations, etc.);
- Logistics

However, the main objective of a HIS is to gather and to display medical information between healthcare professionals in a seamless way. This medical information is currently available through dedicated and specialized applications or software, owned by commercial vendors. Even if the quality of such dedicated software

is acceptable, the main problem faced by HIS managers is the integration of these specialized applications within the HIS, and mainly the communication with the administrative core of the system.

Work-around solutions, however imperfect, do exist to realize such integration:

- Ad hoc solutions, developed by the HIS programmers
- Applications Program Interfaces (APIs)
- Middleware
- Workflows
- Intermediation Platforms

If the workload of computer developers is decreasing in these various applications, the programming complexity is increasing, demanding more and more expertise from the HIS managers.

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CPOES (Computer Prescription Order Entry) represent a typical interoperability problem in hospital information systems: CPOEs are currently necessary to improve the prescription, dispensation, and administration of drugs to patients. Less than 14% of Hospitals have implemented such CPOES, partly due to human and organizational factors. However, technical problems persist; particularly in the need integration and

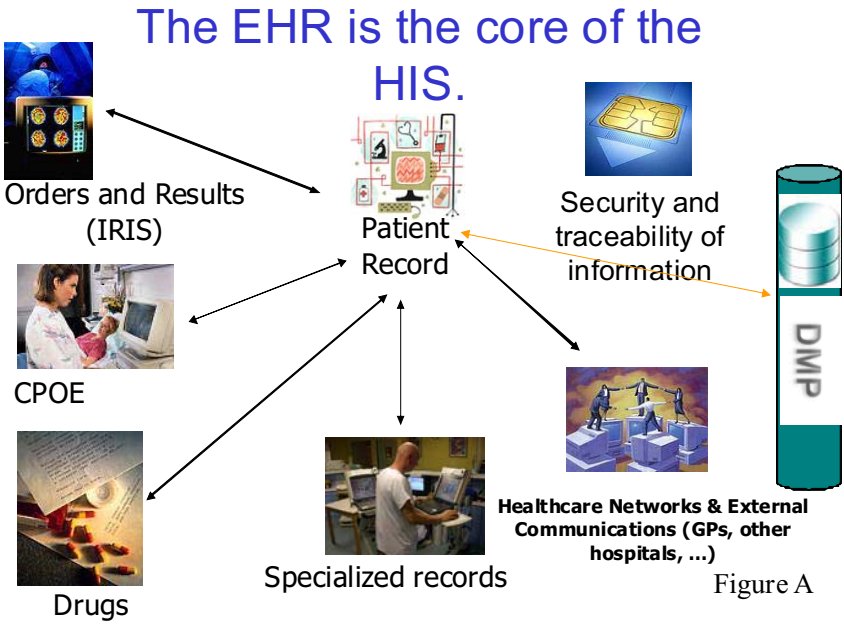


Figure A

the interoperability of such CPOES with the HIS Core (Figure A). Obviously, CPOES utilizes information from the Core System as administrative data, Patient Record, Nurse Record, and Biological Results etc., are sent to the Core System to record the information in the Medical Record -- to store the drug administration in the nurse's record, to meet financial and medico-economical aspects, as well as logistical (pharmacy) constraints.

That is why interoperability is likely to remain as a main challenge in Healthcare Information Systems now, and future years, unless aggressive measures are taken. Solutions exist to allow interoperability between specialized applications and core systems: APIs, middleware, process management systems. Nevertheless, as the complexity of these applications rise, added measures must be taken to ensure the proper performance of interconnected global systems. Moreover, the security, confidentiality, and traceability must be assured.

## 5. Developing interoperable watermarking mechanisms for healthcare by Gouenou Coatrieux

### *5.1. Summary:*

Watermarking has a complementary role with respect to medical information security (integrity, authenticity etc.) and management **[ENST-1]**. Watermarking is the insertion of a *message*, also called *watermark message*, in a host document (image, video, 1D signal, XML, text) in a certain multimedia format. For example, with medical imaging, the message is embedded by modifying the gray sample values of the image in an imperceptible way. Historically, the first application watermarking proposed was for copyright protection. The protection data, or the *watermark data* stays attached, or remains persistent to the signal, whatever the file format conversion, in the distribution chain. Watermarking an image provides access to a communication channel for image authenticity and integrity control.

Watermarking applications in healthcare are relatively new, whereas, it has been more prominent in multimedia circles. Watermarking is receiving popularity in healthcare as a direct result of the mandatory need to preserve the image and interpretative integrity. It is also mandatory that watermark information remain hidden itself, non-interfering/not altering the image and interpretative integrity. Technical solutions to ensure these mandates have been proposed **[ENST-2] [ENST-3]**.

Two significant opportunities for watermarking applications are expected in healthcare. The first focuses on medical image security, where embedding authenticity and integrity proofs relating to the original image, as in the case of a digital signature and image authentication code. Here, the provision of a new security layer ensuring that *watermarking or protection data* is never dissociated from the original information to which it belongs. The second type of watermarking deals with the insertion of metadata in an image, in order to facilitate its management, or give another dimension to original content. In **[ENST-2]**, such meta-data may amount to medical notes, which correspond to the original image or content, which can be used afterwards in remote diagnosis and aid systems.

### *5.2. Interoperability issues in watermarking medical data*

Expected benefits of such a technology use in healthcare require considering several interoperability aspects in relation with watermarking systems (techniques and purpose), handled medical data and medical information systems.

The NHIN distinguishes two types of interoperability according to the IEEE standard 1073: i) functional interoperability devoted to the information exchange

through similar systems with common methods, goals and strategies, and; ii) semantic interoperability, to make effective use of the information, that relies on shared data types and codings for behavioral reproducibility and shared terminologies to ensure preservation of meaning. Interoperability for Digital watermarking and its uses follow the same principles.

- Functional interoperability

One major interoperability issue alludes to the absence of a watermarking standard, which would in-turn permit the existence of an environment, where different methods have the ability to co-exist, or be easily interchanged without problems for the user. The main idea beyond that proposition is to use a standard information reader, with the possibility of using different algorithms for the purpose of embedding information **[ENST-4]**.

- Semantic interoperability

To facilitate semantic interoperability, watermarking applications have to interface with various medical information systems. In this situation, we are forced to look at two types of situations.

The first situation, takes into account the fact that watermarking can provide a private communication channel. As the *watermarking or protection data* is attached to 'a' signal independently, regardless of format, it will be transparent to both, non-compliant and/or legacy systems. However, the issuer of watermarked information must ensure that neither the watermark itself, nor any associated metadata will interfere with the mission goals of non-compliant or legacy systems.

The second situation refer to the integration of watermarking into existing medical standards, considering that this technology can add to, or enhance existing mechanisms to improve medical image protection and/or sharing. Two options are potentially applicable; one considers that the embedded information be handled directly by medical standards, while the other, focuses on achieving complementing objectives with various independent watermarking applications **[ENST-5]**.

With medical imaging, these two situations have to be studied with respect to the well-known DICOM standard. For example, if we focus only on the security aspect, and the first situation with respect to DICOM as an example, authenticity and integrity will be satisfied through the embedding of a message via DICOM compliant means. This additionally means that a message will be formatted in accordance with DICOM specific transfer syntax, containing encoding using DICOM terminology, to get the Image UID and digital signatures. For example, once an original image is accessed through a watermarking plug-in, data is then utilized in accordance with the DICOM standard. The only constraint here for the watermarking method is that the application needs to meet a minimum data-embedding threshold for the application to function properly. In the second situation, DICOM compliant watermarking security tools are able to establish an embedded secure linkage between an image and a medical report, to which it is associated **[ENST-6]**.

### *5.3. Conclusion*

To conclude, watermarking offers new data security and management layers transparently to non-compliant systems. For compliant systems, there is an urgent needs for a watermarking standard, which will provide a framework to change embedding methods without causing problems for a user, where embedding methods may be 'goal specific' to medical information protection and information sharing.

## 6. Making Health Identification Interoperable in Europe
**by Catherine Quantin**

### *6.1. Introduction*

In a recent study, the international patient identification systems of twelve countries were analysed, confirming the variety of patient identifiers, and the difficulty of making health information systems interoperable. In most countries of the North of Europe, a unique patient identifier is either used, or planned, for administrative and health care purposes. However, some countries, like Belgium, are considering the possibility of having different identifiers for administrative, health care and research purposes. In the south of Europe, in countries like Spain or Italy, the health identification number is largely allocated at the regional level.

A solution for interoperability problems here could be to harmonise existing identifiers all over Europe, but this solution presents two major disadvantages. First, if a country has to change its own patient identifier, the problem regarding the management of anterior data has to be solved. Second, the integration of newly accepted countries in the European Union would also raise the question of making changes to their health identification numbers.

For these reasons, we propose:

- to let each country define its own policy of patient identification
- to develop a procedure at the European level to ensure the interoperability of the existing identifiers

### *6.2. Objectives*

Our Proposal is to create a *European Patient Identifier* called the EPI, designed to conform to European and national security regulations, based on two components: existing patients' identifiers, so as not to interfere with national strategies, and another component making it interoperable in Europe. Another important objective of the EPI is to link together and share medical information of patients regardless of their country of origin.

### *6.3. Methods*

Our strategy relies on three pillars. The first pillar is the design of the EPI itself. The second pillar consists of ensuring data security, in order to respect the European directive. The third pillar concerns data linkage, and will ensure the sharing of medical information concerning a given patient, all over Europe.

*First pillar: the EPI design*

The EPI would consist of two major components, in accordance with the system which was developed in a running project supported by the French national research agency. The first component would be based on the existing national or regional numbers so that each country will be able to link new data - with previous data. It would therefore be necessary to make an inventory of all of the systems that exist in Europe. In order to merge a patient's medical information across countries, the second component would mostly be composed of invariable information such as the family-based identifier (a patent - concerning this issue has been obtained).

*Second pillar: security*

Identification and authentication of the patient record will be achieved by creating an individual smart card, on which the EPI will be encoded. To ensure the security of the variables included in the EPI, a patient identity security mechanism that is widely and successfully used in France is proposed for use. For example, the same mechanism is currently applied in health surveillance and in data collection for hospital management purposes. The irreversible transformation of identification data is obtained by using a one-way hash function based on the standard hash function, in accordance with European legislation regarding data protection. After this transformation, a strictly anonymous code is obtained. As this code is unique for a given identity, it is then possible to link the information concerning the same patient, without knowing, or revealing the patient's identity. To avoid dictionary attacks, two keys are generated to ensure that the patient cannot be linked with his medical data without his/her expressed consent.

*Third pillar: data linkage*

The linkage of information from different health structures, of different countries, will be necessary to reconstruct the complete medical history of any patient, for health care or epidemiological purposes. Several linkage methods have been proposed. Deterministic linkage relies on rules that are pre-defined, and most often deals with a single identifier. In contrast, probabilistic linkage takes into account - several identification variables, and uses statistical methods to determine the quantity of information provided by the different identification fields, such as, for example, first and last names and date of birth.

In order to link information coming from different health structures, regarding the same patient, the number of the patient in the country could be used, thanks to a deterministic method. Of course, if the patient is a foreigner, and has not yet been given a national number due to his recent arrival, the family-based identifier could be used. Here the probabilistic method would help to link information, for example, typing errors, which are observed in some of the variables. This method could also be useful to link information coming from different countries, as the same patient would not have the same health identification numbers across countries.

## 7. Conclusion

When discussing patient outcomes from an Electronic or Personal Health Records (EHR/PHR) perspective and their security, it is imperative that we understand a number of elements. For example, the stakeholders as well as the very different dimensions that are data, information, and knowledge transformations, which undergo change - throughout a person's life, influence greatly, how items should be protected and what solutions are needed. For most hospitals, the term EHR system is not necessarily, what it should be. In general, these systems are equal to an automating of Hospital processes - and only that. Such records do not generally contain dental records, or a patient's mental health information. Yet a patient that may be receiving mental health care and anti-depressants in one hospital could easily be treated by another practitioner in the same hospital, without the presence of verifiable, aggregate knowledge. The medication that the new provider is ready to prescribe to the patient in this case, could bring about a negative interaction, when combined with the drug that the patient is already taking -- but it is not documented anywhere in the EHR.

Although information technology and other technologies such as medical devices and pharmaceuticals take a center stage in the current health care delivery system, they are not the only concern in the interoperability conundrum. People and processes are as important -- if not more than technological components, and they are part of the needed solution and discussion. The orchestration and installation of interoperability therefore, takes many different dimensions and forms that go much further than what was covered in this workshop.

On one hand, new ways of delivering healthcare such as telemedicine and homecare for the elderly have created new requirements for medical centers. New types of professionals are now needed in medical centers to provide expertise on expanding IT, communications services, computer science, and other areas. Conversely, new business processes will be required for all new service implementations. As an example, expansion of telemedicine related applications would require for both medical, as well legal reasons, the storage of the "video-sessions" between service/care provider and patient. Newer technologies implemented for diagnosing, treating and curing different conditions may eliminate some of the old and persistent medical errors, but newer service implementations could introduce a whole new generation of errors - if we are not careful.

The general inability for multi-disciplinary, inter-disciplinary thinking, has historically qualified the quietly deceitful, yet, imposingly precipitous nature of this remarkably challenging pursuit of interoperability. *"'Connecting the dots' indubitably commands that we see all the dots there are to see, and not just those that are conveniently positioned, or available,"* says Prof. Dr. Mathews. However, universally, there has been an undervaluing of the level of holistic mental acuity required of those involved in the pursuit of 'connecting the dots,' to find perpetually -- professional and intellectual comfort, being at the intersection of optimal situational awareness, knowledge, tools, techniques, and opportunities among other things. Nevertheless, for organizations, this task is a much easier expressed - than accomplished.

A pattern of organizational behavior, which continues to cater to *convenience oriented thinking,* is both, insufficient and destructive; therefore, it must be wholly discouraged and organizationally banished. Efforts launched to address merely parts of the puzzle may at times be important, but, in no manner should they be construed as being holistic and, or complete. Each of the papers that are summarized herein should

be considered as a part of a larger *need to do.* They represent essential parts, but not the whole.

"The report of my death was an exaggeration," [4] so remarked Mark Twain, when major news outlets falsely reported that he was no longer - among the living. So goes the *potboiler prose* routinely found regarding achievements of interoperability; they are greatly exaggerated. Here, Twain's quotation is noted merely to qualify the eagerness associated with certain reportage. Generally, interoperability in-the-large is thought of as having achieved, if it meets a pin-point objective, yet, fails to meet a larger, *end-to-end* criteria - involving multiple heterogeneous environments of varying scales and vast distances among other things.

## 8. References

[ENST-1] G. Coatrieux, L. Lecornu, B. Sankur, and C. Roux, "A Review of Image Watermarking Applications in Healthcare," in Proc. of the 28th International Conference IEEE Engineering in Medicine and Biology Society, 2006.

[ENST-2] G. Coatrieux, C. Le Guillou, J.-M. Cauvin, Ch. Roux, "Reversible Watermarking for Knowledge Digest Embedding and Reliability Control in Medical Images", IEEE Trans. on Information Technology in Biomedicine, to appear.

[ENST-3] W. puech, G. Coatrieux, "Hybrid coding using encryption, data hiding and compression for the security of medical information", chapitre de l'ouvrage, Compression of Biomedical Images and Signals, Chippenham, UK : ISTE, to appear.

[ENST-4] M. Barni, F. Bartolini, V. Cappellini, A. Piva, "Interoperability Issues in Watermark-Based Electronic Copyright Management", Proceedings of 4th International Conference on Virtual Systems and Multimedia VSMM'98, Gifu, Japan, November 18-20, 1998, Vol I, pp. 140-144.

[ENST-5] G. Coatrieux, C. Quantin, J. Montagner, M. fassa, F-.A. Allaërt, Ch. Roux, "Watermarking Medical Images with Anonymous Patient Identification to Verify Authenticity," Studies in Health Technology and Informatics, IOS Press, To appear.

[ENST-6] J. Puentes, G. Coatrieux, L. Lecornu, "Secured Electronic Patient Records Content Exploitation", book Healthcare Knowledge Management: Issues, Advances, and Successes, Ed. Springer Verlag, 2006.

[4] Mark Twain, New York Journal, 2 June 1897

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# European Projects

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# A Tele-Medicine Service over Satellite Network

Thomas Pliakas[a], Serafeim Dermeitzoglou[a], Christos Papachristos[b], Artur Krukowski[a]
[a] *Intracom Telecoms S.A. (tpli@intracom.gr, sdei@intracom.gr, krukowa@intracom.gr)*
[b] *Hellas Sat S. A. (c.papachristos@hellas-sat.net)*

**Abstract** The main objective of paper is to describe a proposed tele-medicine pilot is for establishing a telemedicine network in a Private Healthcare Organization, to be developed in the frame of the ESA project, HOST[1]. The HOST program focuses on the development of the Hellas Sat commercial offering in end-to-end satellite telecommunication services for supporting the delivery of bidirectional (broadband) applications in Greece, the Balkans, SE Europe, and the Middle East. To this effect a satellite broadband network will be implemented and operated 5 remote sites, three of them acting as trainers and the rest two as trainees The pilot system will allow real time exchanges of medical records to aid tele-diagnosis, co-ordination of medical and administrative processes, tele-assistance using videoconferencing; distant medical equipment or medical records (images and examinations, allergies, medical history, etc) monitoring and real time tele-diagnosis by specialized medical doctors on remote sites.

## 1. Introduction

The development of a HOST end-to-end SatCom service able to a wide range of applications was a result of the market push for applications and generic services in the area of e-Government, e-Business, e-Inclusion/Digital Divide complying also with marketing interests of the Hellas Sat and its partners to support the business case for such an end-to-end service provision.

The 'HOST Service Platform' will be based on DVB-RCS technology, which will support independent networks providing several kinds of applications within the Hellas Sat coverage. The DVB-RCS standard supports bi-directional broadband connectivity via satellite enabling services such as fast Internet access, intranet/VPN for secure connections, multicast and real time applications.

The forward link, from the central Hub, is based on the DVB-S/MPEG-2 data format and is capable of carrying information with bit rates up to 45 Mbps. At the receiving site, each SIT connected to the network is able to upload at up to typically 2Mbps per carrier in the return direction using a Multi Frequency-Time Division Multiple Access (MF-TDMA) scheme.

During the initial stages of the HOST project, a number of pilot trials will be undertaken in the areas of tele-Education, tele-Medicine, e-government, Digital Divide and corporate networks (VPN).The telemedicine pilot project addresses a critical area of services for the Greek and European markets. Taking into consideration the fact that

[1] HOST - HELLAS SAT Offering in Satellite Communications, ESA sponsored project: "Applications: Satcom Network Systems and Services"

Greece has a specific geographical morphology, with many isolated areas, it makes the ideal 'test bed' for the application and deployment of telemedicine services using satellite technologies. With the term "telemedicine service" one describes the total provision of organization and management of medical information and the communication capabilities among geographically diverse users for the common processing of information and the composition of diagnostic reports.

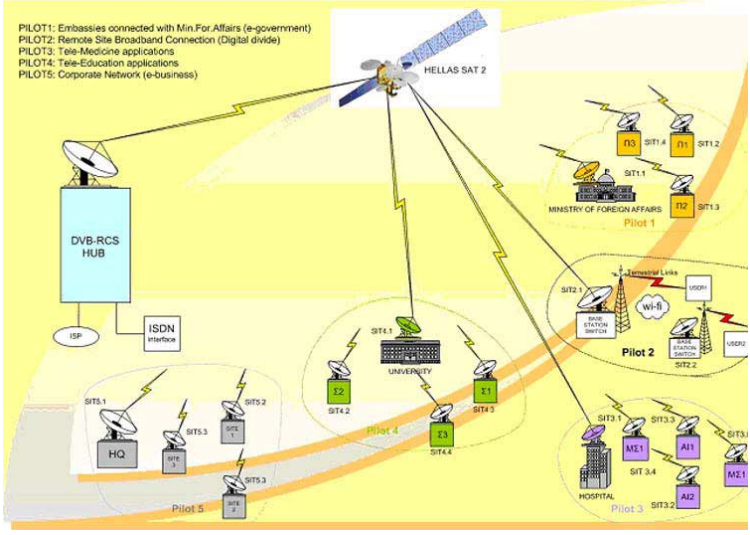


**Figure 1**: HOST: System Architecture

## 2. General Pilot Description

The main objective of the pilot is to establish a telemedicine network in a Private Healthcare Organization. To this effect a satellite broadband network will be implemented and operated between the Ygeias Melathron Hospital, the Thessaloniki and Patras Medical Centers, the Sotiria's 3rd Internal Medicine Medical Unit and the Medical Physics Laboratory of the Athens Scool of Medicine. The pilot system will allow real time exchanges of medical records to aid tele-diagnosis; co-ordination of medical and administrative processes; videoconferencing; distant medical equipment or medical records (images and examinations, allergies, medical history, etc) monitoring and real time tele-diagnosis by specialized medical doctors on remote sites.

The main issue for the hospital is to gain Tele-presence, i.e. to have access to the means for medical data transmission, whereby the patient-information will be transmitted from the central site to the remote sites. The *telemedicine* service will complement existing clinical services, replacing none of them. The goal is to reduce and alleviate patient's discomfort by adopting the usage of Telemedicine Services for a number of cases, where this can be applied.

In terms of the existing infrastructure all participating sites possess PCs while the ***Ygeias Melathron*** (Remote Site A) site has videoconference peripherals too. None of the other end user sites has such a facility. Also, none of the participating sites have either leased lines or routers.

## 3. Pilot Architecture – DVB-RCS

The Service Platform will be based on DVB-RCS technology. The RCS Platform will support independent networks providing different kinds of applications within the Hellas SAT coverage. DVB-RCS provides bi-directional broadband connectivity via satellite with bit rates comparable or exceeding terrestrial systems, enabling services such as fast Internet access, intranet/VPN for secure connections, multicast and real time applications. The configuration of the DVB-RCS system is in the form of star network architecture consisting of a ground station Hub and a number of Satellite Interactive Terminals (SITs). The proposed system is able to support up to 100 simultaneously active SITs and it can be upgraded to support up to 10000 terminals. The forward link, from the central Hub, is based on DVB-S/MPEG-2 data format and is able of carrying information with bit rates up to 45Mbps. In the receiving site, each SIT connected to the network is able to upload up to 2Mbps per carrier in the return direction using Multi Frequency-Time Division Multiple Access (MF-TDMA) scheme.

## 4. User Groups and Roles

Two User Groups will be involved in the telemedicine pilot. The Central Medical Units and the Remote Medical Units. The Central Medical Units will be clinics that incorporate all major medical specialties and the needed sophisticated equipment and will act as the referral points for the Remote Medical Units. Specialized medical doctors will be available to assist remote units, on incidents where teled-diagnosis or a second opinion is judged necessary. More than one Central Medical Units may exist with complementary medical expertise.

The telemedicine user in HOST will be O.A.T.Y.E. O.A.T.Y.E. constitutes the first Federation of Mutual Health Funds in Greece. The Health Funds T.Y.P.E.T. (Mutual Health Fund of the National Bank of Greece Personnel), A.T.P.S.Y.T.E. (Bank of Greece Employees Health Fund) and T.Y.P.A.T.E. (Health Association of Employees of the Agricultural Bank of Greece), jointly signed the Statutes of Constitution (Memorandum) of the Federation of Greek Mutuality. In 1999, E.D.O.E.A.P. (United Press Organization of Supplementary Insurance and Medicare) joined the Federation, as its fourth member.

The four Greek Health Funds operate according to the Model of Mutualism, providing their members with health services, complete medico-pharmaceutical and hospital insurance, without receiving any social and financial resources from the State, while preserving its Self-Governed and independent character, based on the principle of Solidarity. In the Telemedicine pilots the Athens School of Medicine will also participate with two user terminals. It is expected that the Athens Medical School will provide expert opinion in the project's everyday run. It is probably worthwhile to note that some of the Professors and heads of Athens Medical School are already collaborating with Ygeias Melatron clinic and therefore their involvement will be facilitated and augmented throughout the project.

### *4.1. Central Medical Units*

#### *4.1.1. The Ygeias Melatron Clinic*

This is a totally owned by TYPET private non-profit 80-bed clinic with all major medical specialties, equipped with sophisticated medical equipment (CT, Mammography, bone mineral density etc) and 30 full-time and part-time physicians and dentists. The Clinic has traditionally strong relations with Athens University Medical School and some of its collaborators hold academic positions in the latter. Ygeias Melatron Clinic constantly tries to give the best treatment both to the in-patients and out-patients. The clinic will act as a Central Medical Unit and will be the referral center for Patras and Thessalonica medical centers.

#### *4.1.2. The 3rd Department of Medicine, Athens School of Medicine*

The 3rd Department of Medicine was founded in 1990. It is sited in the second floor of Building Z, at Sotiria General Hospital. The first head of the Department was Professor G. Arapakis (1990-1993), thereafter Professor T.D. Mountokalakis (1993-2004) and the current head is Associate Professor Apostolos Acheimastos.

Being a University Department, the 3rd Department of Medicine has daily lectures and practice sessions for students of the Medical School and of the School of Dentistry. The lectures cover all fields of Clinical Examination, Diagnosis, and Therapy within Internal Medicine. There are 42 beds for in-patients care, and outpatient clinics for internal medicine, endocrinology, infectious diseases, diabetes mellitus, rheumatic diseases, hypertension, hematology and oncology. There is a 30-beds day clinic that treats patients with neoplastic diseases (solid tumors and hematological diseases). There are four independent units: hypertension, gastroenterology, hematology and oncology.

With regard to the personnel, there are eighteen qualified doctors: nine members of Athens Medical School, five external fellows and four members of NHS. There are twenty junior doctors doing their practice, as part of their specialization to Internal Medicine, Hematology, Gastroenterology, Pneumonology, Cardiology and Oncology. There are four biologists and numerous nurses. The Sotiria's 3rd Internal Medicine Medical Unit can provide 2nd opinion in cases requiring assistance or evaluation in the spectrum of Internal Medicine (Cardiology etc).

#### *4.1.3. The Medical Physics Laboratory, Athens School of Medicine*

The Medical Physics Laboratory (MPL) was established in 1979. Its main educational activity is to offer compulsory education in Medical Physics to the undergraduate medical students of Athens University Medical and Dental Schools. Since 1996, MPL is the coordinator for the Medical Physics - Radiation Physics postgraduate course organized jointly by 5 Greek Universities and 2 Research Centers. The School of Medicine has a scientific staff of 630 persons and a student population of 6.325.

The Medical Physics Department (MPL) has a long experience in Telemedicine projects. Further, as it is located in the main Medical University Campus, it can act as a physical "meeting point" of other than those served by Sotiria's 3rd Internal Medicine medical specialties, of the university colleagues assisting the project (i.e. Biochemistry, Microbiology, Surgery etc). Thus, a more global medical support of the project can be anticipated.

### *4.2. Remote Medical Units*

#### *4.2.1. The Medical Center of Patras*

On April 2002 O.A.T.Y.E. inaugurated the openings of its Health Center in the city of Patras. The creation of Patras Medical Center constitutes the first Federal project. Its operation is intended to cover the members' needs for health services. The Patras' Medical Center is equipped with excellent medical personnel and medical equipment, providing the medical specialties of: Dermatologist, Cardiologist, Dentist, Orthodontist, Orthopedist, Oculist, Pathologist and Otolaryngology's.

#### *4.2.2. The Medical Center of Thessalonica*

This medical Center operates under the auspices of TYPET but it is planned to gradually accept outpatients from the other three members of OATYE. The center, located in the heart of the town, has all the facilities and Departments that Patras Medical center has, and additionally it covers more medical specialties (Biochemistry, Microbiology, X-Rays etc).

## 5. Services and Applications Offered

The telemedicine service is analyzed in the following applications: ***Core Telemedicine***, ***Telemedicine for patient's awareness*** and ***Videoconferencing***.

### *5.1. Core Telemedicine*

The "core telemedicine" application allows for medical data transmission that is used by the medical staff in order to provide Tele-consultation and Tele-diagnosis. It is used for the collection of the patient examinations and other related data that describe a specific medical case. This collection of data is routed through the service provider to an expert, who can diagnose and provide a second opinion. The collected data may refer to all or to a subset of the following:

- Medical record,
- Patient presence (video, images)
- Vital signs,
- Medical data depending on the case:
  - Biological sound from electronic stethoscope
  - Cardiogram
  - Microbiology analyses
  - Medical images (e.g. X-RAY images compliant with a DICOM. standard)

To accommodate the collection and transmission of the above a wide range of types of data need to be supported: text, numeric, image, video, and X-ray images. No specific transformation of information elements will be needed before presentation, apart from user-friendly presentation of the data. The data will be collected by the Remote Medical Units and will be forwarded either off-line to the Central Medical Units or in real time during an established session. The Remote Medical Units will request the initiation of a session with a Central one and the system will be capable to locate the most appropriate Central Medical Unit for the specific case. The selection can be based upon configurable criteria such as medical stuff availability at the given time or predefined areas of expertise in different medical centers.
During an established session the following features will be available:

- Video and Audio conferencing (Real time collaboration using audio and video. Allows for patient's presence monitoring, and document view.)
- Chat (Exchange of text messages during a conference.)
- File Transfer (Send a data file in the background to the conference participant.)
- Program Sharing
- Whiteboard (Real time collaboration via graphic information.)

### *5.2. Telemedicine for patient's awareness*

Through the Telemedicine platform it will be possible to provide programmed lectures to patients/customers in the remote medical units on critical medical issues. These remote lectures will make use of Videoconferencing facilities and applications.

### *5.3. Videoconferencing*

The "videoconferencing" application is based on the H.323 video conferencing and the T.120 data conferencing standards. Unlike the "real time collaboration", of the core telemedicine application when using the "videoconferencing" application, the users cannot view patient related information, but only common data. This application serves as a point to point teleconferencing tool for the administrative personnel dispersed at the 3 sites (Athens, Thessaloniki, and Patras), and is used when the administration of the Federation wishes to discuss important issues using Teleconference facilities.

### *5.4. Service Requirements*

The desired bandwidth is the maximum possible to support video, audio, images and file transfer, i.e. c.a. 1Mbps (bi-directional) to start with. The architecture of the pilot service is being depicted at Figure 2.

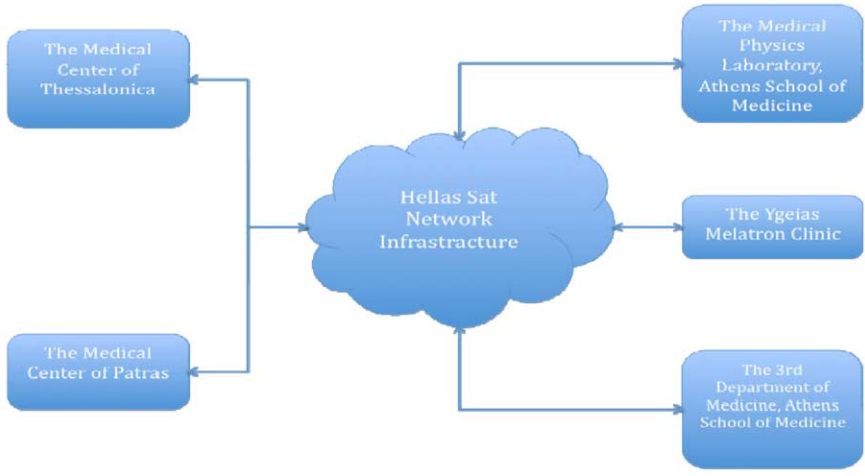


**Figure 2**: Tele-medicine pilot architecture

Figure 3, depicts the Slide Show tool, with which user (trainer or active trainee) has the opportunity to display his slides into Power Point files mode.

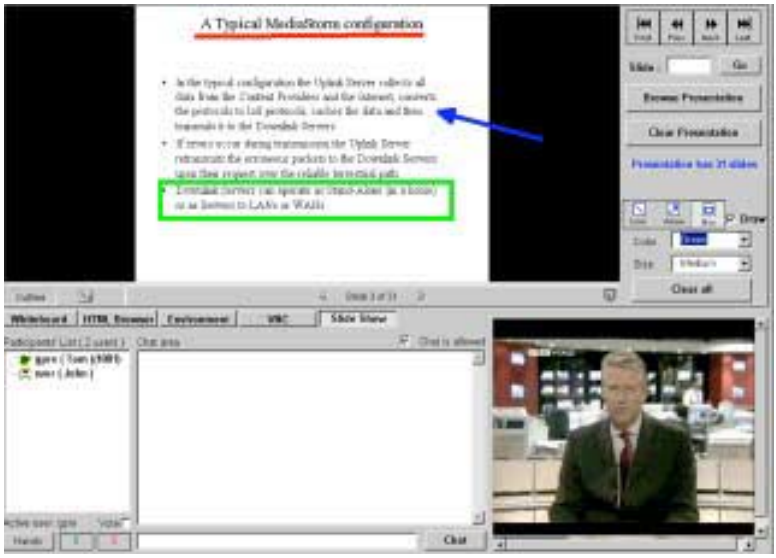


**Figure 3:** Tele-medicine Application - Shared Presentation Tool

By using *Browse Presentation* button he may select the Power Point file that he desires to open and with *Clear Presentation* button the display area is cleared either preparing a new one to open or to move to another tab, By pressing the buttons *First, Prev, Next* and *Last* he moves to the first, previous, next and last slide correspondingly. Also user may type the number of the slide into the *Slide* edit box, and to "jump" to the preferable slide. When a presentation opens, user gets information about the number of the slides that this presentation contains Active user is able to draw simple geometrical shapes on the slides, by checking *Draw*. It makes his presentation more easy and efficient because the rest of the users pay attention to the annotated places of the slide. These geometrical shapes may be a line (for instance, if user wants to underline a sentence), an arrow (if he wants to guide the rest of the users to a particular part of the presentation) and a box (if he wants to surround an area of the slide).

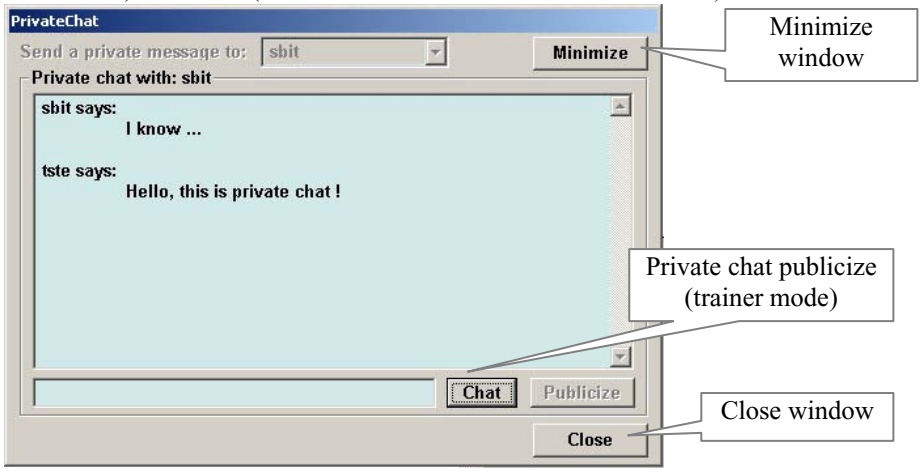


**Figure 4:** Private chat form

Except public chat there is the capability for private chat between users is also provided. By right clicking on trainer's mode, private chat form appears where users can type and send the message. Also active users can do the same with a right click on trainee's node. Except the presentation and a private chat, the telemedicine application provides also applications like Whiteboard, WEB or file browsers (Figure 4).

*5.4.1. Application specific*

- PC and Videoconference peripherals: camera, microphone and speakers
- Blood pressure monitoring device
- Biomedical equipment:
  - Digital Electronic Stethoscope, e.g. measure heartbeat
  - ECG
  - Vital signals monitoring
- Other medical equipment (depending on availability) connected on PC after signal has been "digitized", e.g. digital medical images (DICOM standard)

Locally Interconnected PCs or video projection facility is connected to support the lecture session. In addition to the above equipment a server PC will be installed in one of the Central Medical Units.

## 6. Pilot Operations Procedure

For the pilot operations the requirement/prerequisites are:

- Familiarization of the IT and (2) Medical doctor responsible with the system.
- Quality assurance factors to ensure patient safety, accuracy and performance of equipment and user acceptability of the monitoring: (i) informal consent from patient in order to participate in the Telemedicine pilot and (ii) periodical quality control from I.T. experts.
- Approval from the Hellenic Personal Data Protection Authority for the processing of sensitive data in a Telemedicine program (Greek Legislation, Law 2472/1997).
- A secure software solution for sharing electronic healthcare information over the Internet. More specifically the system must comply with the Health Insurance Portability and Accountability Act (HIPAA) and meet with provisions that require the adoption of detailed security standards for electronic data interchange (EDI).

During the pilots session based usage is required. Initially the service will be used on a weekly basis (once a week) and gradually usage will be increased depending upon needs. Pre-scheduled grand-round clinical events will be dealt with, i.e. no particular nor emergency incidents but instead on a per case basis. As the pilot moves along, other cases will be handled as well.

## 7. Evaluation Method

Evaluators from the medical and the technical field will conduct the evaluation of the medical services offered via the network. During the pilot operation the telemedicine service will be evaluated in terms of the offered services' effectiveness as well as of the

infrastructure reliability and usability as well as for patient's data security. More specifically the following will be assessed:

1. Quality and usability of the available tools
2. Overall quality and effectiveness of the service
3. User acceptance and satisfaction both by the medical personnel and patients
4. Overall patient's data security.
5. Tests will be implemented to ensure the proper function of the following system's components:
6. Physically protected servers with a mechanism for limiting electronic access
7. Public Key Infrastructure with 128-bit encryption
8. Digital certificates issued by a certification authority
9. Strong authentication enabled by cryptographic camouflage technology
10. Portability for secure connections from remote locations

The infrastructure needed for the utilization of the service will be assessed in terms of:

- Reliability of the overall network
- Ease of use and administration of the service

The above parameters will be valued against the cost of installation and operation of the service. The cost benefit of the telemedicine Pilot will provide useful information for fine tune the commercial offering of the service.

Interviews, self-reporting and observational methods will be used on the basis of their feasibility and appropriateness for each user group Suitable tools, e.g. questionnaires, will be developed prior to the operation phase and they will be fine tuned during the pilot operation according to the special needs of each user group.

## 8. Anticipated Results & Conclusions

Medical video transmission is a key issue for the successful deployment and usage of telemedicine applications. Video compression schemes have been introduced in order to achieve better content delivery and quality preservation at the same time according to the requirements of the corresponding e-health application. The offered service will allow the telemedicine user to provide equal opportunities to all of its customers simplify the procedure for typical examination diagnosis due to geographical dispersion and finally lead to the reduction of cost for the provision of healthcare. Using evaluation data the Service will be trimmed to the market needs and a commercial offer will be build, enabling hospitals and remote clinics with:

- Diagnosis Decision Support
- Medical information exchange
- Tele-consultation
- Management procedures support

## References

[1] Cai Meng; Tianmiao Wang; Wusheng Chou, Sheng Luan, Yuru Zhang, Zengmin Tian, "Remote surgery case: robot-assisted teleneurosurgery", In Proc. of IEEE International Conference on Robotics and Automation, vol. 1, pp. 819-823, 2004.

[2] Arata J., Takahashi, H., Pitakwatchara, P.;\, Warisawa, S., Konishi, K., Tanoue, K., Ieiri, S., Shimizu, S., Nakashima, N., Okamura, K., Young Soo Kim, Sung Min Kim, Joon-Soo Hahm, Hashizume, M.,

Mitsuishi, M., “A remote surgery experiment between Japan-Korea using the minimally invasive surgical system”, In Proc. of IEEE International Conference on Robotics and Automation, vol. 1, pp. 257-262, May 2006.

[3] Peng, R., Sclabassi, R.J., Qiang Liu, Justin, G., Mingui Sun, “Synthesizing Multi-View Video Frames for Coding Patient Monitoring Video”, In Proc. of 28th Annual International Conference of IEEE Engineering in Medicine and Biology Society, pp. 5157-5160, Aug. 2006.

[4] Qiang Liu, Sclabassi, R.J., Mingui Sun, “Change detection in epilepsy monitoring video based on Markov random field theory”, In Proc. of 2004 International Symposium on Intelligent Signal Processing and Communication Systems, pp. 63-66, Nov. 2004.

[5] Qiang Liu, Mingui Sun, Sclabassi, R.J., “Illumination-invariant change detection model for patient monitoring video”, In Proc. of 26th Annual International Conference of IEEE Engineering in Medicine and Biology Society, pp. 1782-1785, 2004.

[6] ITU-T Rec. & ISO/IEC 14496-10

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# An Assisted-Living Home Architecture with Integrated Healthcare Services for Elderly People

Andy MARSH[a], Christos BINIARIS[a], Dimitrios VERGADOS[b], Arnold EPPLER[c], Christoforos KAVVADIAS[d], Olaf BIGALKE[e], Eric ROBERT[f], Boro JERABEK[g], Alevizos ALEVIZOS[h], Michael CARAGIOZIDIS[i]
[a]*VMW Solutions, Romsey, UK*
[b]*University of the Aegean, Samos, Greece*
[c]*Alcatel-Lucent, Stuttgart-Zuffenhausen, Germany*
[d]*Teletel S.A., Athens, Greece*
[e]*Siemens, Bocholt, Germany*
[f]*Thales, Lambersart Cedex, France*
[g]*Gorenje Group, Velenje, Slovenia*
[h]*Health Center of Vyrona, Athens, Greece*
[i]*Thoss & Partner GmbH, Ludwigsburg, Germany*

**Abstract.** Since the population of elderly people grows absolutely and in relation to the overall population in the world, the improvement of the quality of life of elderly people at home is of a great importance. This can be achieved through the development of generic technologies for managing their domestic ambient environment consisting of medical sensors, entertainment equipment, home automation systems and white goods, increasing their autonomy and safety. In this context, the provision intelligent interactive healthcare services will improve their daily life and allowing at the same time the continuous monitoring of their health and their effective treatment. This work is supported by the INHOME Project EU IST-045061-STP, http://www.ist-inhome.eu.

**Keywords**. Healthcare Services, Patient Monitoring, Assisted Living at Home

## Introduction

Europe's ageing population is a challenge for both its social and health systems. By 2020, a quarter of Europe's population will be over 65. Spending on pensions, health and long-term care is expected to increase by 4-8% of GDP in coming decades, with total expenditures tripling by 2050. Similarly, by 2050, elderly people aged between 65-79 years old are expected to make up almost a third of the population which is a rise of 44 per cent compared to the start of the century. As for very elderly people (80+), their share of the total population could grow by 180 per cent over the same period. The majority of older people do not yet enjoy the benefits of the digital age such as low cost communications and online services that could support some of their real needs; only 10% use the internet. Severe vision, hearing or dexterity problems, frustrate many older peoples' efforts to engage in the information society. According to findings of the

Center for Disease Control, nearly three quarters of elders over the age of 65 suffer of one or more chronic diseases. The majority of the growing elder population worldwide requires some degree of formal and/or informal care either due to loss of function or failing health as a result of ageing.

The cost and burden of caring for elders is steadily increasing. If given the choice, many elders would prefer to lead an independent way of life in a residential setting with minimum intervention from the caregiver. Ambient Assisted Living (AAL) programs are intended to address the needs of this increasing elderly population, to reduce innovation barriers of forthcoming promising markets for the various target group populations, but also to lower future social security costs on the long run. The major challenges of AAL research programs are to extend the time elderly people can spend in their home environment by ameliorating their level of autonomy and assisting them in carrying out simple or even more complicated everyday activities.

It is a challenging issue for someone to deal with the special needs of elderly people especially in the home healthcare monitoring and treatment. The goal of the INHOME project is to provide the means for improving the quality of life of elderly people at home by developing generic technologies for managing their domestic ambient environment, consisted of white goods, entertainment equipment and home automation systems with the aim to increase their autonomy and safety [1], [2]. Monitoring of different types of chronic diseases of elderly people at an in-home environment relies heavily on patients' self-monitoring of their disease conditions [3]. In recent years, telemonitoring systems, that allow the transmission of patient's data to a hospital's central database and offer immediate access to the data by the care providers, is of a great importance [4], [5].

From the healthcare delivery system point of view, an evolving picture of the patient at any given time will be produced, taking into account diagnoses and treatments, successes and setbacks [6]. The system would assess the current level of functionality and interactively coach the patient to higher levels of functionality. The consistency of continuous monitoring would eliminate much of the inaccuracy from the current random interactions between patients and physicians [7], [8]. Periodically and as determined by medical parameters and health plan factors, this data would be reviewed by trained professionals to such evaluation process.

The User Group is provided by the Health Centre of Vyronas (HCV), which is specialised in the provision of medical services to elderly people at home. The medical personnel are also involved in the requirements specification for aged people. The institute offers some of the houses under surveillance to be used as application testbeds and assist in the evaluation phase of the INHOME technology. This paper presents the overall network architecture, discusses the health and activity monitoring framework, describes the A/V streaming and personal data acquisition by medical devices within the home environment, and finally summarises project's current conclusions.

## 1. Needs and Challenges

Responding to the needs and challenge of Europe's growing ageing population, the European Commission has recently adopted a European Action Plan for "Ageing Well in the Information Society". These new EU initiatives will contribute to allowing older Europeans to stay active for longer and live independently. Improved quality of life and

social participation for older people, as well as more efficient and more personalized health and social services are the main key-points of these initiatives.

Regulatory authorities believe that remote home health monitoring solutions provide an opportunity to make care delivery more efficient without reducing the overall quality of care. However, such programs face significant challenges. Although some pilot programs have produced promising results, two key conditions have yet to be fulfilled a) governments have so far failed to establish permanent reimbursement mechanisms for these solutions, and b) public and private constituents have not reached consensus on the most feasible business models.

Nevertheless, health monitoring systems have been developed as a solution for these continuously rising demands for specialized elderly care in the home environment. Challenges in research regarding health monitoring, have grown and expanded in developing technological solutions for in-home monitoring of residents in order to provide quality of life indicators. The most important aspects of the various in-home monitoring systems are characterized of a suite of low-cost, non-invasive sensors and a data logging and communications module, in addition to an integrated data management system, preferably linked to the Internet.

By using appropriate data analysis tools, important observations can be made from the activity data generated by a monitored individual. These observations include: general health and activity levels, activities of daily living, index of well-being, and a measure of the decline in ability over time. These observations may yield early indicators of the onset of a disease. Additionally, a sudden change of activity or inactivity can indicate an accident. Although all similar systems are not appropriate or meant as an emergency prompt system, a caregiver could receive alerts over the Internet or urgent notifications over the phone in case of such sudden accident indicating changes. Software tools can generate reports of health/activity indicators and the overall well being of an individual.

Recent advances in telemedicine, including sensor, communication, and information technologies have created opportunities to develop novel tools enabling remote management and monitoring of chronic disease, emergency conditions, and the delivery of health care. In-home monitoring has the added benefit of measuring individualized health status and reporting it to the primary care providers and caregivers alike; allowing timelier and targeted preventive interventions.

Noninvasive health status monitoring technologies could provide effective care coordination tools that have a positive impact on the perceived quality of life of monitored individuals, as well as the strain levels of their informal caregivers, and may have a positive impact on the participants' health related quality of life. Health status of the elderly in their living environment is a lengthy and costly process that involves numerous stakeholders. If the technology is to be mass produced, widely deployed and utilized by different user groups, the technology has to meet certain feasibility criteria, including being acceptable, useful, and potentially beneficial to all the different users. Some of the more important challenges for the use of health care monitoring technology could be outlined in the following key-points:

- Reduced cost of care, which is particularly high for older adult populations.
- Reduced burdens on the informal caregiver, and hence reduced stress and improved mental and physical health conditions.

- An extended healthy, active and dignified life for the elderly that can be widely accessible to the low-income strata of society.
- Improved informal care effectiveness without increasing intrusion.
- Involving the care recipient in health promoting activities and decision-making.
- Delayed admittance to specialized institutions, and hence a reduced cost of formal elder care.
- Reduced formal care burdens, and hence improved formal care.
- Implemented in simple low-cost sensor technology, which also makes it affordable to the lowest income earners.
- Adaptively retrofits into existing home structures, with minimal impact, modification and cost.
- The data-mining component could yields unique health status reports that can be made available to the occupants, their physicians and medical advisors as well as their family members.
- The system should be customizable to the individual's needs, as well as different cultural needs.

## 2. The Overall Network Architecture

The project identified the need for several devices, sensors and terminals to be integrated for enabling the different kinds of identified services for the elderly people. The overall network architecture with all involved device categories and intermediate network entities is shown in Figure 1. The concept of a centralized gateway as communication and interworking entity is utilized. In this scenario, the gateway is the only device directly connected to the Internet and external service providers with the rest of the home devices connected to the gateway. All messages issued by the devices are routed through the gateway and there has not been envisioned direct communication flow between the devices for this project. The residential gateway undertakes the role of coordinating information requests, it establishes the connection to appropriate content servers and forwards the requests of the service applications. The architecture is also enhanced with the introduction and usage of a Multi Service Terminal which acts as a repeater, increasing the limited coverage of the Bluetooth devices and sensors. The gateway processes as well as forwards the information either to WAN and to LAN entities [9].

Ethernet, Wireless LAN (WLAN) and Bluetooth are used as communication technologies. Since most devices are equipped with Ethernet sockets and pre-configured cabling is available, the installation procedure becomes rather easy. Also, nearly all the gateways available on the market are equipped with a build-in wireless network interface. The dominating technology for WLAN communication follows the IEEE standards 802.11 a, b, g or n.

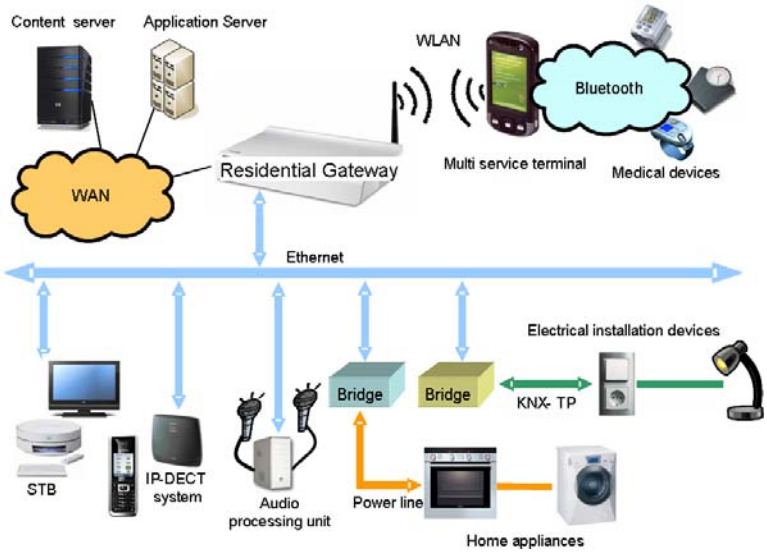


**Figure 1.** The INHOME Overall Network Architecture and Devices

The INHOME services are communicating both internally within the home network as well as with the external world. This means that communication must not be limited to in-home data flows only. Depending on the service, communication must be secured to guarantee a level of intimacy. Only user authentication and authorisation can grant access to personalized services. The INHOME residential gateway is the central entity in the home networking environment, deploying the services and facilitating the communication with the external world. The gateway simultaneously functions as both client and server to the other nodes on the network. The peer node functionality is supported by OSGi, which is capable to host both server parts (Web Servers, Custom Servers etc.) and client parts (UPnP, Web Services, custom clients, HTTP clients etc.). Additionally, the residential gateway is hosting data such as related to the user (user profiles, policies etc.), multimedia data (photos, videos etc.), etc.

Services composition involves the user and a service synthesis environment interacting for the production of a personalised service specification. This specification is consistent with the capabilities of the service execution platforms in use and the user profile stored in the identity management module of the residential gateway and will be produced by a Service Synthesis module located on the Residential gateway. The service composition functionality is being used by the application level of the INHOME gateway for providing AAL services to elderly people. Figure 2 depicts the architecture of the INHOME Residential Gateway and the services supported.

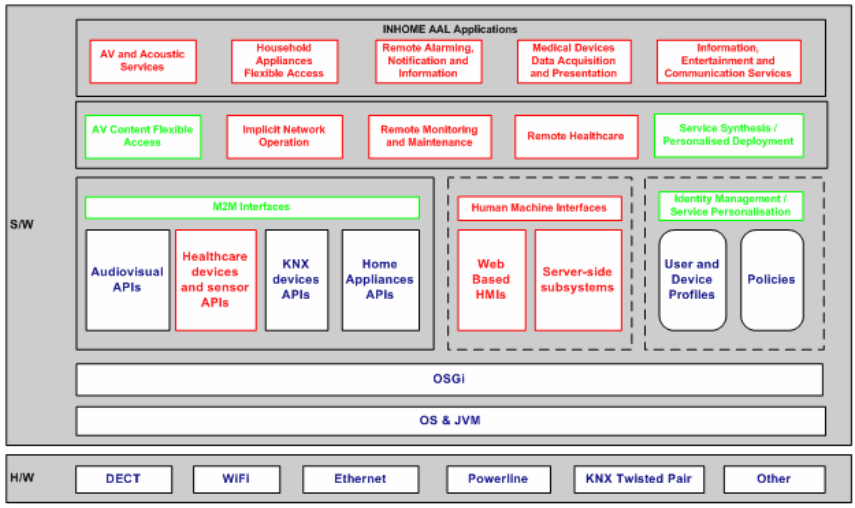


**Figure 2.** INHOME Residential Gateway Architecture and Services Supported

## 3. Health and Activity Monitoring Framework

The healthcare services of INHOME are developed by utilizing various medical devices. For measuring blood pressure, body weight and electric cardiac values special types of devices are needed with a build-in data transmission interface. An example of a monitoring framework is shown in Figure 3. The Bio-sensor can provide various measures like heart beat, blood pressure or glucose ratio measures depending on what is the most relevant for the monitored user. The video sub-system typically consists of an IP-capable camera that can be controlled from the Health Centre.

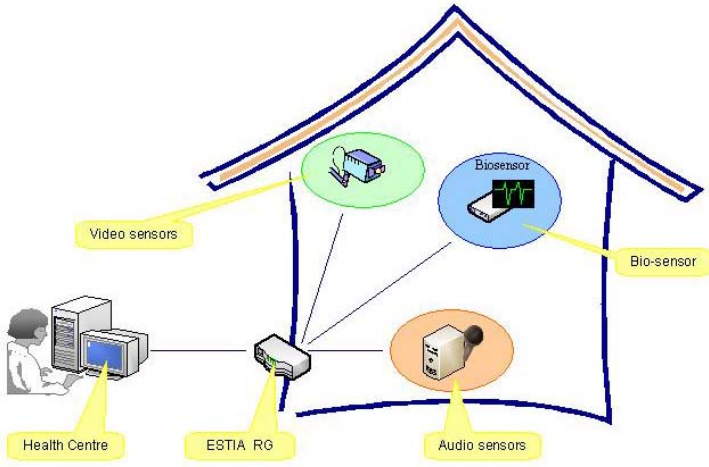


**Figure 3.** Health and Activity Monitoring Framework

The medical devices should be capable to communicate with the INHOME platform using a wireless channel. Bluetooth Technology covers most of the requirements for wireless connectivity, power consumption, and allows ease of setup for a wireless sensor network, offering efficient device and service discovery mechanisms [10]. For this reason, most of the wireless communication related to the acquisition of data from medical devices and sensors is covered with the use of Bluetooth technology.

### *3.1. Personal Data Acquisition by Medical Devices*

A service based on the acquisition of data from medical devices operating in the user's environment is developed. The INHOME architecture is responsible to acquire the data from the medical devices. Afterwards, a check for possible alarm conditions, related to the values of the measurements, takes place. In case that some alarms exist, some automatic actions take place, enabling the person to contact the physician. The elements participating in this showcase are illustrated in Figure 4 and highlighted as:

- The medical devices, which are used to perform measurements such as blood pressure, cardiac pulse, body weight etc.
- The INHOME terminal which is responsible to communicate with the devices for acquiring those measurements.
- The residential gateway which is responsible to run services based on the data produced by the medical devices.
- The TV device which is responsible to display the measurements in a user friendly manner.
- The DECT phone which enables the user to contact his/her physician.

The information flow, related to personal data acquisition by medical devices within the home environment, is depicted in Figure 5. When a measurement is performed using one of the medical devices or sensors, a communication is established with the INHOME terminal for uploading the relevant data.

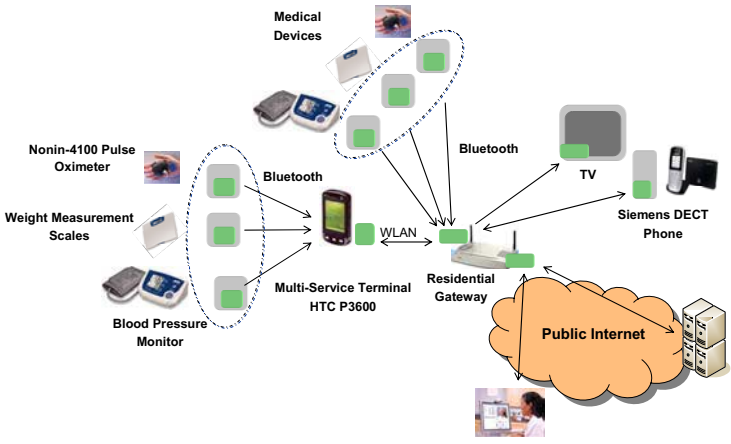


**Figure 4.** Medical Devices Connectivity

This procedure requires the implementation of the most of the times proprietary device communication protocol at the side of the terminal. The Bluetooth communication is used to directly transfer this information to the gateway or through the INHOME terminal. The INHOME terminal is also used as an intermediate collection point due to the fact that it is carried by the user and it can be in the proximity of the medical devices.

In the case that there was only a direct Bluetooth communication with the gateway, the Bluetooth connectivity would not be always guaranteed, since the medical device could be out of the Bluetooth coverage of the gateway. After having acquired the data from the medical devices, the INHOME terminal sends this data through a WLAN communication to the residential gateway, which in turn processes this data. Some key processing is related with the identification of alarm values based on the normal range for each type of measurement, the user profile and updates that can exist from the doctor. The service execution in the gateway is also responsible to send the data to the TV, enabling the user to view the values and assisting the elderly people as vision capabilities are reduced. Upon the detection of an alarm condition, the service in the gateway is also responsible to take appropriate action according the medical case and user. For example, discover the phone number of the physician, which maybe stored locally or at a remote location, send the phone number to the DECT phone allowing the user to avoid the manual dialing of the number or even call directly the doctor, etc.

In order to achieve the acquisition of data from the medical devices, one has to implement the communication protocol of each device which is most of the times proprietary and also non-disclosed by the device vendor. The INHOME terminal executes a J2ME (Java2 MicroEdition) software module which is capable of communicating with each medical device and acquire the relevant data from it over Bluetooth. The alternative approach of direct communication with the residential gateway was performed with the development of the communication module as an OSGI bundle and executed at the gateway.

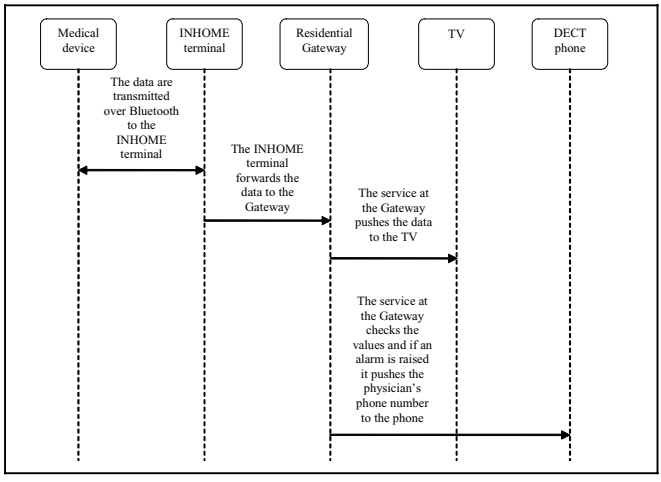


**Figure 5.** Personal Data Acquisition Showcase

### *3.2. Flexible A/V Stream Handling*

The user, through the INHOME mobile terminal, selects through an easy to use User Interface (UI), the person that wants to have a video call with and optionally the terminal on which the video telephony stream should be displayed. A user will be able to perform an A/V session either via a TV set or the INHOME mobile terminal. Additionally, a user will have the capability to transfer A/V streams between TV set and INHOME terminal and continue with the same A/V session (Figure 6). The user will be able to activate a session handover of the AV content, for example when moving from the garden (and utilizing the INHOME mobile terminal) to the living room (TV set) and vice versa [1]. This allows media streams to follow the user to different terminals and places within the home environment.

From a technological point of view the A/V stream could be delivered to any capable device within the household but the focus is on the most relevant devices for the target user group. This is believed to be the TV set, attached to an appropriate set-top-box (STB) and the INHOME mobile terminal. Every user within the home environment will have a personal ID stored in his/her profile maintained at the residential gateway. The gateway incorporates the necessary mechanisms to support a simple-to-use user identification, and implement the automatic configuration of the associated system components, based on the specific user profile.

A streaming server application shall be responsible for the consolidation and controlled distribution of the content. The server, based on the characteristics of the selected terminal, appropriately formulates the content, making optimal utilization of resources while achieving the best possible user experience. The discussed scenario involves the bidirectional handling of video streams. More specifically, the stream from the medical centre is handled like any other entertainment-related A/V stream. However, the stream that goes from the house to the medical centre may also be in need of handling by the system [2].

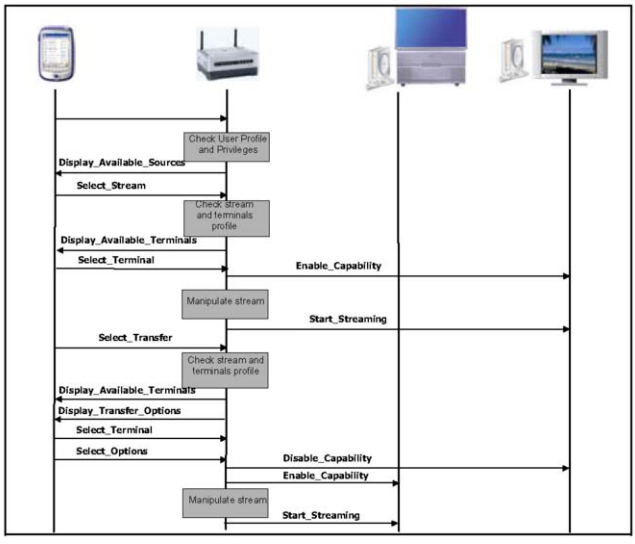


**Figure 6.** A/V Session Initiation and Handover

From this point of view, the stream is not handed over from one terminal to another, but instead, the source may also be changed from the integrated camera on the mobile terminal, to a fixed, higher quality camera inside the house. In addition, when medical equipment interfaces to expose its measurement results, this information is transferred to the medical centre either synchronous or asynchronous to the video stream. This information may or may not be superimposed, depending to the different scenarios. When it is not superimposed, it can be stored for later retrieval or it can be illustrated in a separate "window" resulting in the display of mixed A/V and text information received from the medical devices on the physician's terminal. During each step of the handover, the user is presented with the best available choices (e.g. temporary handover, end temporary handover, pause, etc.) thus avoiding to clutter the limited screen area of the INHOME terminal with the entire options set offered by the A/V environment. Emphasis is put on simplicity, so the user can select for an A/V session, chooses the source (person, video, etc.) and, based on the profile of the user, the session starts on the default terminal with the default options.

1. The user selects the audio/video telephony function on the INHOME terminal. A message is sent to the gateway containing user information.
2. The gateway checks which media sources are available for this user and sends back a list of sources e.g. medical center, pharmacy, relatives.
3. The list is displayed on the screen and the user selects his preferred stream. This information is sent to the gateway.
4. After verifying stream requirements and terminal capabilities, the gateway sends back a list of terminals which fit to be used.
5. The user selects the terminal which is the most convenient for him/her and the gateway enables the capabilities of this device.
6. In case that the selected stream does not fit to the capabilities of the device, the gateway will manipulate (transcode, transrate) the media stream and will start the streaming.
7. If the user has to move to another room, the user will be able to carry the running A/V stream with him/her by selecting "Transfer" on the INHOME terminal which sends this request to the gateway.
8. The gateway itself verifies again which terminals could be used and sends back a list to the user's INHOME terminal. Additional options like "transfer in pause mode" will be reported to the user.
9. The user selects the new terminal and the preferred option by sending back an appropriate message to the gateway.
10. The gateway disables the old terminal and enables the newly selected.
11. Depending on the capabilities of the new terminal the stream has to be manipulated in another way by the gateway. Then, the gateway starts the A/V stream.

## 4. Conclusions

An intelligent healthcare service environment will produce an evolving picture of a patient at any given time, taking into account diagnoses and treatments, successes and setbacks. Continuous interaction, collecting of information, detailed patient status and appropriate user profiling would allow the immediate and more effective treatment of the patient. In this paper, an interactive healthcare services environment for assisted living at home is presented. Concerning the relevant underlying technology employed,

OSGi, Java and Web Services are gaining a lot of publicity. They have not yet fulfilled their full potential, but as evolving technologies they are believed to be maturing into standards that would be influencing, if not dominating home networking and home mobile environments. This research work has been developed under the INHOME project, the goal of which is to provide solutions for improving the quality of life of elderly people at home by integrating and introducing generic technologies for managing their domestic ambient environment, comprised of white goods, entertainment equipment and home automation systems with the aim to increase their autonomy and safety and for providing at the same time appropriate medical assistance, when needed.

## Acknowledgement

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## References

[1] INHOME Deliverable D-2.2: INHOME Architecture Specification - http://www.ist-inhome.eu.
[2] INHOME Deliverable D-2.1: Architecture Requirements & Showcases - http://www.ist-inhome.eu.
[3] V. Rialle, J.B. Lamy, N. Noury and L. Bajolle, "Telemonitoring of patients at home: a software approach", Computer Methods and Programs in Biomedicine, Vol. 72, Issue 3, 2003, pp. 257-268.
[4] R. Lee, H. Chen, C. Lin, K. Chang and J. Chen, "Home Telecare System using Cable Television Plants – An Experimental Field Trial", IEEE Transactions on Information Technology in Biomedicine, Vol. 4, Issue 1, 2000, pp. 37-43.
[5] N. Maglaveras et al., "Home care delivery through the mobile telecommunications platform: the Citizen Health System (CHS) perspective", International Journal of Medical Informatics, Vol. 68, Issue 3, 2002, pp. 99-111.
[6] E. Kyriacou et al., "Multi-purpose HealthCare Telemedicine Systems with mobile communication link support", Healthcare Engineering OnLine, Vol. 2, Issue 7, 2003.
[7] C.S Pattichis, E. Kyriacou, S. Voskarides, M.S. Pattichis, R. Istepanian and C.N. Schizas, "Wireless Telemedicine Systems: An Overview", IEEE Antennas & Propagation Magazine, Vol. 44, Issue 2, 2002, pp. 143-153.
[8] M. Engin, Y. Yamaner and E. Z. Engin, "A biotelemetric system for human ECG measurements," Measurement, Vol. 38, Issue 2, 2005, pp. 148-153.
[9] D. Vouyioukas, I. Maglogiannis, D. Vergados, G. Kormentzas and A. Rouskas, "WPAN's Technologies for Pervasive e-Health Applications – State of the Art and Future Trends", Journal for Quality of Life Research, Vol.3, Issue 2, May-June 2005, pp. 198-204.
[10] ESTIA Applications, Requirements, and Architecture - http://www.ist-estia.org/deliverables/estia_alcatel_wp2_d21_final.pdf
[11] ESTIA Functional Specifications - http://www.ist-estia.org.

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# Knowledge Management

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# Functional and Technological Description of a Real-Time Data Management System for Telehealthcare

Fabiola FERNÁNDEZ[1], Laura M. ROA[1, 2], Manuel PRADO[2, 1]
[1]*Biomedical Engineering Group, University of Seville, Seville, Spain*
[2]*Network Center of Biomedical Research in Bioengineering, Biomaterials and Nanomedicine (CIBER-BBN)*

**Abstract**. In health systems, there has been an emergence of new types of data and new technologies that allow continuously monitoring the status of the patients and make easy the achievement of real time information. The storage of all the acquired information makes possible to identify trends in medical data by means of new Clinical Decision Support subsystems. Current knowledge management solutions are specific, proprietary and closed and can not perform real-time analysis to improve the patient's diagnosis or treatment. There are neither solutions that integrate the large amount of heterogeneous information that nowadays are available in health environments. To overcome these objections, this paper proposes a new approach to design a data management system in a telehealthcare system with specific real-time constraints on knowledge acquisition and generation. It is a preliminary study and presents the main features of the system architecture and a preview of the technological solution implemented.

**Keywords.** Telehealthcare, real-time databases, data management systems, knowledge generation.

## 1. Introduction.

In general terms, knowledge management involves the strategies and processes for identifying, capturing, structuring, sharing and applying an individual's or an organization's knowledge to extract competitive advantage and create sources of sustainable growth [1]. In the health systems, there has been an increment in the information that can be processed and stored with computer-based tools, mainly due to the increase of diagnostic and therapeutic procedures. This increase of information did not lead to a corresponding increase of health care professionals, so they usually have to deal with much higher amount of data compared, e.g. to health professionals of twenty years ago. In addition, we have to refer to the emergence of new data at the molecular level, e.g. as DNA or protein data. Consequently, information management in the healthcare sector has become even more multifaceted and complicated [2].

All these changes are being faced by the use of Information and Communications Technologies (ICTs). The interaction between the twin revolutions of ICTs and Telecommunications has enabled healthcare technologies based on concepts such as Electronic Patient Records (EPR) and Electronic Health Records (EHR) to become a reality. Some authors have conducted studies to provide technological, organizational

and managerial perspectives on how best to incorporate knowledge management in healthcare [3]. These studies pointed out the difficulties in transforming and transferring individual knowledge into organizational knowledge and the existence of a very limited research (particularly empirical data) to guide healthcare stakeholders, both from an academic and organizational perspective. In addition, there are some other specific challenges related to the use of ICT in health, such as the complexity of medical information, data entry problems, security and confidentiality concerns or the absence in many countries of a unique national patient identifier [4].

Moreover, the health system is rapidly becoming a knowledge-based community that connects hospitals, clinics, pharmacies and customers to share knowledge, reduce administration costs and improve quality of care. Thus, the success of healthcare depends critically on the collection, analysis and seamless exchange of knowledge within and across different institutions. Consequently, the design of health care system must not only provide a technical infrastructure, but must also integrate the system applications in order to acquire data that are accurate, complete and stored in compatible formats [1].

The emergence of new technologies able to continuosly monitor the health status of patients makes easy the achievement of real time information. Among these technologies we highlight the wearable devices with sensors and without manual intervention. These become particularly important when patients are suffering from a chronic disease such as diabetes, kidney failure, arteriosclerosis, or chronic obstructive pulmonary disease. In [5], the authors presented a system whose main purpose was to capture blood-pressure, heartbeat and weight data generated by special sensors in a reliable way. The platform recorded information in near real time, so medical staff were able to see trends in the data within minutes of a measurement being taken. In other recent work, the authors introduced a portable patient unit (PPU) and a wearable shirt to monitor electrocardiogram (ECG), respiration (acquired with respiratory inductive plethysmography), and activity. In this system, the PPU analyzes physiological signals in real time and determines whether the patient is in danger or needs external help [6]. Another real-time monitoring device is being developed by the Biomedical Engineering Group (GIB) of the University of Seville, called Intelligent Accelerometer Unit (IAU) [7]. It is a wearable sensor for homecare movement monitoring and is integrated in a Wireless Personal Area Network. It acquires accelerations, analyzes them to detect impacts and transmits all this pre-processed information in response to requests from a master unit.

The storage of all the information acquired from these kinds of devices and their integration with other EPR, make it possible to identify trends in medical data, which can help with formulating research priorities, identifying the causes and epidemiology of diseases, assessing the effectiveness of clinical procedures and customizing patient data in order to know what type of information is relevant to a user and how that information is presented. This implies the development of expert knowledge based subsystems that provide the ability to do sophisticated analysis on different type of knowledge. Clinical Decision Support (CDS) systems meet these functions. CDS modules can simultaneously access and combine relevant information from a vast number of medical knowledge resources [8, 9].

However, there are some objections in the acquisition, management and generation of knowledge in current health systems. One of the major drawbacks is that despite modern devices perform data acquisition in real time, which can be send synchronously to database managers, the last ones only store and manage a fraction of the received

data. This is due to the compromise between processing speed and management of rich information in object relational database management systems. This limitation impedes a more complete use of vital health monitoring signals, which could be processed within mathematical models to generate knowledge emphasizing the dynamics of the physiological and artificial systems related to patients.

To overcome these problems, current telehealthcare systems need real-time data managers that allow interacting with other different systems, since patients' information reside in highly heterogeneous environments and independently of each other. Also, it is necessary a management system with a good efficiency/cost relation in terms of access to information at all levels.

This paper proposes a new approach to design a data management system in a telehealthcare system with specific real-time constraints on knowledge acquisition and generation. This work is a preliminary study and presents the main features of the system architecture and a preview of the technological solution implemented. To make this possible, it has been studied the case of Nefrotel. In general terms, Nefrotel is a novel personalized telehealthcare system for nephrology and it is being developed in the GIB [10]. This approach presented is organized as follows. In the first place there is a description of the scenario and a functional analysis based on the requirements posed by the project but adapted for a generic telehealthcare system. As a result, it is proposed an architecture and a technological solution for a manager system based in the real-time data management in industrial environments.

## 2. Analysis of functional specifications for a Real-Time Data Management System.

### *2.1. The scenario of the telehealthcare system: Nefrotel.*

Nefrotel belongs to framework of the telehealthcare projects that provide real-time knowledge generation of the status of the patient. Its objectives are focused on research and development of a methodology and a set of technological specifications to provide a system with the following functions: advanced monitoring of the patient and therapy machines, quantification of the adequacy of dialysis, integration of multiscale biomedical knowledge and accessibility to Nefrotel by the patients under the requirements of reusability, interoperability and scalability of the resources [10].

The telehealthcare system is composed by three scenarios: the Point of Care (POC), the Professional User Interfaces (PUI) and the Telehealthcare Center (THCC). They are described with more details in [10, 11]. These modules include two subsystems. The first one consists of Patient Physiological Images (PPI), which are autonomous computational modules that generate online customized information by means of dynamic mathematical models adaptable to the patient [11]. The second one is a subsystem based on SCADA concepts. The presence of a monitoring system with similar features to those of an industrial SCADA is explained in [12]. This module is implemented in Linux, using a General Public Licence (GPL) development platform, ProcessViewBrowser, and providing the system open-architecture characteristics, enabling a better interconnection among systems of different manufactures and including the concepts of portability, interoperability, scalability and expansion. Its main objectives are the generation and administration of alarm events and the management of all the information related to the patient, both the real time data and the historical records.

According to the specifications of the subsystems in Nefrotel, a data management system has been designed to meet the needs required by the telehealthcare system, specifically by the PPI and SCADA monitoring system.

### *2.2. Functional analysis of the Data Management System.*

Nefrotel is organized in three data processing layers: a smart and adaptive sensor layer, the PPI layer and a clinical and technical decision and analysis support layer. Before proposing a design for the data manager, it was necessary to find out the data types that will be treated by each of the system layers. In the case of Nefrotel, we have, mainly, the following types of information:

- Health information. This type of data includes the information off-line, introduced through the PUIs with a delay with respect to the time instant when they were acquired, e.g. blood analysis, as well as the data which are taken in real time from different devices connected to the THCC and included in the sensor layer.
- Data related to the devices and the system processes configuration.
- Patient demographic information.
- Useful information about professional users.
- Alarms. Ranging from those generated by devices connected to the system, either medical or mechanical alarms, to those from the processes themselves of the system.

Depending on the needs of each layer, the data manager must be able to provide the required functionality:

- The layer of sensors basically feeds the system with the patient's clinical information in real time. It also provides, in some respects, the configuration data of the devices which patients are connected to, useful for customizing the patient's treatment.
- The objective of the PPI layer is the discovery of new knowledge about a patient. To do so, the computational modules access monitoring variables and generate real-time information.
- The layer of decision support will lead to specific data warehouses and help in the detection of devices and sensors malfunctions, involved in the treatment of the patient.

The requirements for monitoring data acquisition and generation of knowledge in real time as well as the necessary interaction among the different layers of information processing, make it imperative to have, within the telehealthcare system, a data management system that allows access to data in real time, either in reading or writing, by all the processes involved in the system.

Before suggesting a possible technological solution to the problem, it was essential to provide the system manager with the same features of open architecture that were imposed in the development of the supervision module of the telehealthcare subsystem [12].

With all this background, in order to cover all the identified needs, a system manager based on a hybrid solution is proposed. The idea of a hybrid solution for the data manager emerged from the fact that Object-Relational Databases (ORDB) are not designed for real-time operation and current real-time databases do not provide functions for the processing and permanent storage of the information[13]. In the next

section, the architecture of the solution adopted is described, as well as its main technological features.

## 3. The Hybrid Management System in Nefrotel.

The Hybrid Management System (HMS) is divided into two subsystems. The first one follows the ORDB model, supported by PostgreSQL. The second one is a real-time data manager implemented with shared-memory tables. Both of them are wrapped by a single layer of agents which are in charge of all the data management.

This design allows, on the one hand, keeping the value of ORDBs and on the other hand, operating in real time with the variables stored in shared memory, which is an essential point to meet the telehealthcare system's requirements.

### *3.1. Description of the architecture of the Hybrid Management System.*

As it is mentioned before, the HMS has three parts: an ORDB management system, a shared-memory segment and a number of agent processes.

*The Object-Relational Database*

The ORDB is in charge of storing different types of data used in the system, which are discussed in a previous section: patients' demographic and health information, alarms, devices configuration data and professional users' information involved in the system.

In addition to managing all these data in real time, the system manager keeps a flexible historical record. This means that the system, apart from a conventional historical data recording, allows the professional user to request to record certain information useful for him/her, despite the fact that the user does not have administrator permission in the system.

With regard to alarms situations, the system manager makes a continuous monitoring of the alarm status in real time and takes the information associated to the corresponding historical record once it has been processed.

Although storing information from the patients EHR is not a mission of the database (DB), it is necessary to record such data that may be relevant to meet the goals of the telehealthcare system related to improving the treatment and diagnosis of the patient. Furthermore, it maintains a relation between the own identifiers from the system and any other identifier that refers to a database already installed in the place where the HMS was implemented.

Storing professional users' information is an interesting point because it allows recording some useful information like the different types of access to the system for each user, enabling the permission restriction to certain parts of the system, only accessible to administrators. Moreover, it is possible to get real-time full-knowledge about a user who has recognized, for example, an alarm previously generated. Finally, it makes a record of the requests made by users to the database, thus providing personalized information from each user depending on the applications received in the HMS.

To conclude, the system also has the capability to launch triggers and procedures, which improve the performance of the database. At the same time, it is possible to plan optimizations in the execution of search and data updates.

*The Shared-Memory Segment*

The shared memory segment consists of a set of tables that have a data structure that needs to be accessed and / or updated in a very fast way by the system processes.

*The layer of Agents*

As mentioned above, the layer of agents wraps ORDB and shared memory tables. In this case, the agents are processes of the HMS that meet the following objectives:

- Boot. Initializing the data structure of the shared-memory segment and synchronization mechanisms needed to manage it.
- Periodic transfer of data between memory and ORDB.
- Support tasks for the historical records: for example, dumping data from memory and administrating the flexible historical records.
- Management requests, locals or remotes, that the rest of the telehealthcare system processes make to the HMS, either memory or ORDB.

*3.2. Technological aspects of design.*

As it was done in a previous work about the monitoring system based on SCADA concepts [12], it was imposed as a priority that the system meets the minimum requirements associated with open architectures, so in the first place, the system must be portable to other operating systems and easily scalable. With these issues in mind, a system has been designed using Open-Source tools to enable it to be integrated into any operating system.

The HMS is implemented on a UNIX-based operating system, in particular, Debian Linux distribution, in its last stable version, Etch. The software packages that are supplied with the stable releases of Debian have demonstrated their robustness as agreed by both developers and users of the system [14]. This philosophy has made Debian one of the Linux distributions with more advantages in terms of quality and stability.

On the basis of choosing an Open-Source database management system, it has been chosen PostgreSQL to implement Nefrotel ORDB. MySQL and PostgreSQL lead the market of licence-free data management systems and there are many studies that compare the features and performance of both managers.

While MySQL gives a high speed and reduced consumption of resources both in CPU and memory, PostgreSQL provides other benefits in terms of referential integrity, characteristics that in the case of MySQL is ignored and left to the application developer [15]. In conclusion, PostgreSQL appears to be a better option in the case of databases where data consistency is essential despite its lower speed compared to MySQL.

To implement the database, it has been used PostgreSQL version 8.1.8 (at the time of this work, the latest version available is 8.3 [16]). We are restricted to this version because it is included with Debian Etch, ensuring a version sufficiently tested and free of errors.

For the programming of the involved processes in the HMS, it was chosen the C programming language at the expense of other high-level languages such as Java. There are many performance studies that have been made between C and Java. For

Debian machines one of the last benchmarks that were made continues to show that C is better than Java in CPU time and memory usage [17].

The solution proposed for the shared-memory management, regarding the access and synchronization mechanisms, consists of using POSIX system calls. POSIX is a standard developed by the IEEE Computer Society with the reference-IEEE P1003. The IEEE Std. 1003.1-2001 defines the standard interface of an operating system and its environment, including a shell and common utility programs to support the portability of applications at the Source Code level. The use of POSIX gives to the system the capability of being portable to other operating systems [18].

## 4. Discussion and Summary.

Current telehealthcare systems not only give an online patient monitoring or manage EHR information, but can also generate real-time knowledge to improve the patient's diagnosis or treatment. Nefrotel meets these objectives and also provides a multilevel patient knowledge and uses advanced CDS subsystems. According to the needs generated by the requirements of Nefrotel, the foundations for designing a real-time data management system have been laid based on the database systems of industrial environments.

Modern SCADA systems in industrial environments enable having a real time database integrated in the monitoring system. These databases usually have two types of storage systems, one for static information and another for data that have very strong time constraints. Normally, the real-time data have a short life cycle and in a synchronized way, they are transferred to the static database periodically [19]. In the case of a telehealthcare system like Nefrotel, there are different processes that need a real-time database: PPIs, sensors, SCADA system, CDS modules, etc. However, they also need that certain data can be accessed in a fast way, before they are merged with static data register such as a historical record.

The authors in [19] explain that a SCADA system accesses the real-time data through a real-time task management and other parallel process, which the authors called I/O dispatch, and it is responsible for dumps from memory to the ORDB. In Nefrotel, the philosophy is different, as there is a layer of agents that wraps both shared-memory tables and the ORDB. In this way not only serves the orders from the monitoring system, but directly manages requests from the rest of the system processes. In addition, internally, as it is already explained, there are processes that perform transfers from memory to the database and vice-versa.

On the other hand, it must be said that there are some solutions of real time databases, but these are commercial database systems or databases that are embedded in monitoring systems. As an example we can refer to Raima DB Manager (RDM) and Streambase [20, 21]. In RDM, it is given the option of choosing an embedded database or a database server, but none of them provide the features of an Object-Oriented database. Something similar occurs with Streambase, which is not really a database. Instead of storing information, it is a server for processing, mixing and matching, huge and voluminous streams of real-time data. What it does allow is connecting with some databases that store historical data with which to operate (Sybase RAP, Vertica and IBM's DB2). This philosophy and the RDM are turning away from the goals of Nefrotel HMS.

In conclusion, with this preliminary study for a real-time data management system, it has been possible to adapt the management concepts of real-time databases of modern SCADA systems in industrial environments to a telehealthcare field without losing functionality provided by the ORDB. In addition, a single database can maintain a large amount of very heterogeneous information providing the system with a real capability to integrate patient knowledge. At present, the GIB is working on the closure of the management system implementation and on a benchmark study, comparing it with other managers.

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## References

[1] R. Bose. Knowledge management-enabled health care management systems: capabilities, infrastructure, and decision-support. *Expert Systems with Applications* 2003; 24(1):59-71.

[2] R. Haux. Health information systems - past, present, future. *International Journal of Medical Informatics.* 2006; 75, 268-281.

[3] A.N. Dwivedi, R.K. Bali and R.N. Naguib. Implications for Healthcare Knowledge Management Systems: a case study. *Conference Proceedings: Annual International Conference of the IEEE Ha sido posible adaptarEngineering in Medicine and Biology Society.* 2005; 6, 5668-5671.

[4] J. Grimson, W. Grimson and W. Hasselbring. The SI challenge in health care. *Communications of the ACM.* 2000; 43, 48-55.

[5] C. Kirsch, M. Mattingley-Scott, C. Muszynski, F. Schaefer and C. Weiss. Monitoring chronically ill patients using mobile technologies. *IBM Systems Journal*. 2007; 46, 86.

[6] J.W. Zheng, Z.B. Zhang, T.H. Wu and Y. Zhang. A wearable mobihealth care system supporting real-time diagnosis and alarm. *Medical & biological engineering & computing*. 2007; 45, 877-885.

[7] J.G. Jiménez, L.M. Roa and M. Prado. Design of a Second-Generation Intelligent Accelerometer Unit for the Monitorization of Human Movement. *Annual Conference of the Spanish Society of Biomedical Engineering, CASEIB 2007 (in Spanish)*. 2007; 56-59.

[8] D. Wilson, D. O'Sullivan, E. McLoughlin and M. Bertolotto. Case-Based Decision Support for Intellingent Patient Knowledge Management. *3rd International IEEE Conference on Intelligent Systems.* 2006; 130-135.

[9] K. Ramamritham, S.H. Son and L.C. Dipippo. Real-Time Databases and Data Services. *Real-Time Systems*. 2004; 28, 179-215.

[10] M. Prado, L. Roa, J. Reina-Tosina, A. Palma and J.A. Milan. Renal telehealthcare system based on a patient physiological image: a novel hybrid approach in telemedicine. *Telemedicine journal and e-health : the official journal of the American Telemedicine Association.* 2003; 9, 149-165.

[11] M. Prado, L. Roa, J. Reina-Tosina, A. Palma and J.A. Milan. Virtual Center for renal support: technological approach to patient physiological image. *IEEE transactions on bio-medical engineering*. 2002; 49, 1420-1430.

[12] F. Fernández, M. Prado and L. Roa. Supervisory System in a Telehealthcare Project: Methodology and Development Tools. *Annual Conference of the Spanish Society of Biomedical Engineering, CASEIB 2007 (in Spanish)*. 2007; 44-47.

[13] M. Prado, L. Roa and J. Reina-Tosina. Methodological issues for the information model of a knowledge-based telehealthcare system for nephrology (Nefrotel). *Medical and Care Compunetics 3. Amsterdam, Holanda. Ios Press.* 2006, 96-107.

[14] J. Fernández-Sanguino. Study of the tools used in the source-free Debian GNU/Linux Project. Technical University of Madrid (in Spanish). 2001. Available on the web:

http://www.ibiblio.org/pub/linux/docs/LuCaS/Presentaciones/200103hispalinux/jfs/html/t1.html Last visited: March 2008.
[15] V. Aguilar and P. Suau. MySQL vs. PostgreSQL. September, 2006. Available on the web: http://www.fedora-es.com/node/189 Last visited: March 2008.
[16] The PostgreSQL Global Development Group. PostgreSQL 8.1.9 Documentation. 1999-2005. Available on the web: http://www.postgresql.org/docs/8.1/static/index.html Last visited: March 2008.
[17] The Computer Language Benchmarks Game. C GNU gcc vs. Java 6 – Server in a Debian machine. February, 2008. Available on the web: http://shootout.alioth.debian.org/debian/benchmark.php?test=allgcc=&lang=&lang2Java Last visited: March 2008.
[18] The Open Group Base Specifications Issue 6. IEEE Std. 1003.1-2001 Edition . 2001-2004. Available on the web: http://www.unix.org/single_unix_specification Last visited: March 2008.
[19] J. Wu, Y. Cheng and N.N. Schulz. Overview of Real-Time Database Management System Design for Power System SCADA System. *Proceedings of the IEEE SoutheastCon*. 2006; 62-66.
[20] Raima Database Manager. Birdstep Technology ASA. Available on the web: http://www.birdstep.com/database/Products/ Last visited: March 2008.
[21] Streambase Server. Streambase Systems, Inc. Available on the web: http://www.streambase.com Last visited: March 2008.

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# Validating a Knowledge Transfer Framework in Health Services

Doug ORENDORFF[1], Alex RAMIREZ[2] and Elayne COAKES[3]
*Sprott School of Business, Carleton University and Westminster Business School, Westminster University*

**Abstract.** The study of knowledge transfer (KT) has been proceeding in parallel but independently in health services and in business, presenting an opportunity for synergy and sharing. This paper uses a survey of 32 empirical KT studies with their 96 uniquely named determinants of KT success to identify ten unique determinants for horizontal knowledge transfer success. These determinants, the outcome measure of Knowledge Use, and separate explicit and tacit transfer flows constitute the KT Framework, extending the work of previous KT framework authors. Our Framework was validated through a case study of the transfer of clinical practice guideline knowledge between the cardiac teams of selected Ontario hospitals, using a survey of senders and receivers developed from the KT literature. The study findings were: 8 of 10 determinants were supported by the Successful Transfer Hospitals; and 4 of 10 determinants were found to a higher degree in the Successful than non-Successful transfer hospitals. Taken together, the results show substantive support for the KT Framework determinants, indicating aggregate support of 9 of these determinants, but not the 10th – Knowledge Complexity. The transfer of tacit knowledge was found to be related to the transfer of the explicit knowledge and expressed as the transfer or recreation of resource profile and internal process tacit knowledge, where this tacit transfer did not require interactions between Sender and Receiver. This study provides managers with the building blocks to assess and improve the success rates of their knowledge transfers.

**Keywords.** Horizontal knowledge transfer, health services, case study, clinical practice guidelines, tacit knowledge transfer

## Introduction

Health professionals work in a very knowledge intensive environment requiring them to keep current and to continue to apply this continually evolving knowledge base. Thus, a central challenge in this health services environment is Knowledge Translation, defined as "the iterative, timely and effective process of integrating best evidence into the routine practices of patients, practitioners, health care teams and systems, in order

[1] Corresponding Author: Doug Orendorff B. Math, MBA, MHA, Ph.D. doug.orendorff@rogers.com.
[2] Alex Ramirez B.Sc., M.Sc, Ph.D. Sprott School of Business. Alex_Ramirez@Carleton.ca.
[3] Elayne Coakes BA, PGCertEd, MSc, FHEA, MBCS, Ph.D. Westminster Business School, Westminster University coakese@westminster.ac.uk.

to effect optimal health care outcomes and to maximize the potential of the health care system" [1]. Successful Knowledge Translation requires knowledge transfer, "the technical process that brings information from scientific research to caregivers" [2]. Thus, one avenue to address improved Knowledge Translation is through a better understanding of the determinants of, or the barriers to, knowledge transfer success in health services.

Business oriented knowledge use derives from a similar context. Organizational knowledge is seen as "the most strategically important of the firm's resources" [3] and the principal source of sustainable competitive advantage [4]. Based on innovation and corporate entrepreneurship, this organisational knowledge, along with the introduction of the right products at the right time, in the right markets and with the right supply chain, provides for near-term competitive advantage and long-term viability [5]. This competitive advantage can be sustained by reinvesting in these competencies through knowledge creation and knowledge transfer activities [6].

The study of knowledge transfer (KT) has proceeded independently in the environments of health services and business, each with their own vocabulary, motivations, theory and research; despite very similar theoretical underpinnings and approach in business [7] and in health services [8]. In each environment, KT theory has approached the problem of transfer success predominantly from the perspective of identifying barriers to, or determinants of, a successful transfer, e.g., in business, 'perceived reliability of the source' [9] and in the health services, 'recommendation is based on scientific evidence' [10].

Our survey of KT literature used a 2007 Proquest search of ABI/Inform for knowledge transfer articles, a review of recent KT dissertations, input from a leading Knowledge Translation researcher [11], and an iterative citation review to identify further referenced KT studies. A total of 963 articles were reviewed from which we identified twenty-eight business and four health services qualitative and quantitative empirical studies (all listed in column 4 of Table 3) which together have identified 96 uniquely named determinants [12]. Our survey also identified five independent frameworks or groupings of KT success determinants [9,10,13–15], each with a related but different set of KT success determinants, a subset of which was found to be empirically significant in each study.

This diversity and variance suggests the need for a comprehensive yet parsimonious Knowledge Transfer Framework that integrates the work of these research environments, empirical studies and frameworks. This paper develops such a conceptual framework of KT; describes the qualitative method for better understanding and testing this KT Framework; presents the findings; briefly discusses these findings; and then identifies the implications of our study for health services managers.

## 1. Conceptual Framework

Our study follows two KT empirical traditions. First, we study KT success from the perspective of identifying the determinants of transfer success isolating those determinants significant in achieving KT success [9]. Second, we investigate groupings of

these determinants [9,10,13–15] "that allows their relative influence to be measured" [16].

We developed our KT Framework by selecting a parsimonious set of transfer success determinants. We organized the potential 96 determinants from the 32 empirical studies into the Communications Model [17] based determinant categories of: knowledge, sender, receiver, sender-receiver relationship, transmission, and context, identified in aggregate from the work of Szulanski [9]; Argote, McEvily and Reagans [18]; Cummings and Teng [14]; and Ko, Kirsch and King [15]. These categories are presented in column 1 of Table 3. Within these categories the individual determinants were grouped according to their definition and use and a single determinant selected to represent each logical grouping, e.g., knowledge codifiability out of knowledge articulability, knowledge age, and precisely described. This result is presented in column 2 of Table 3, where the full list is described in Orendorff [12]. Inclusion in the KT Framework (column 3 of Table 3: yes or no) was determined according to the following four criteria synthesized from the empirical KT literature. The determinant must: a) be within the scope of the KT Framework fitting within one of six categories (knowledge, sender, receiver, sender-receiver relationship, transmission, and context); b) have been found to be significant by at least two empirical KT studies [19] where empirical support is shown via highlighted study author names in column 4 of Table 3; c) have a documented theoretical basis [18], preferably depicting a universal construct applicable to the business and health services environments; and d) represent a unique and non-overlapping KT Framework element [20].

Thus, the ten determinants of the Knowledge Transfer Framework discussed in this paper are: (1) Knowledge Codifiability; (2) Knowledge Complexity; (3) Prior Related Knowledge; (4) Unlearning Capacity; (5) Positive Receiver Motivation; (6) Perceived Credibility of Source; (7) Sender-Receiver Distance; (8) Relationship Quality; (9) Richness of Transmission Channels; and (10) Supportive Organizational Context.

The identification of KT determinants (independent variables) and KT outcome (dependent variable) is not sufficient to develop a comprehensive KT Framework. If one considers knowledge as "a construction of reality rather than something that is true in any abstract or universal way" [21] where this entails a tacit element of knowledge since "a wholly explicit knowledge is unthinkable" [22], then the transfer of the knowledge must include some tacit elements since "explicit knowledge cannot be transferred unless its underlying tacit knowledge is transferred, exists or is recreated" [23]. Therefore, there are two dimensions to our KT Framework: 1) the ten KT determinants and the KT outcome; and 2) the explicit and tacit KT flows. The explicit knowledge flow is, we propose, unidirectional from Sender to Receiver while the tacit knowledge flow is bidirectional due to the expected enabling communication between Sender and Receiver [24]. Our KT Framework is shown in Fig. 1.

Following the empirical KT literature, our Framework is intended to apply to both horizontal KT (involving knowledge already in use in a similar organization) and vertical KT (knowledge put to use for the first time, transferred from a dissimilar unit, for example, between a research unit and practicing clinicians) [16,25].

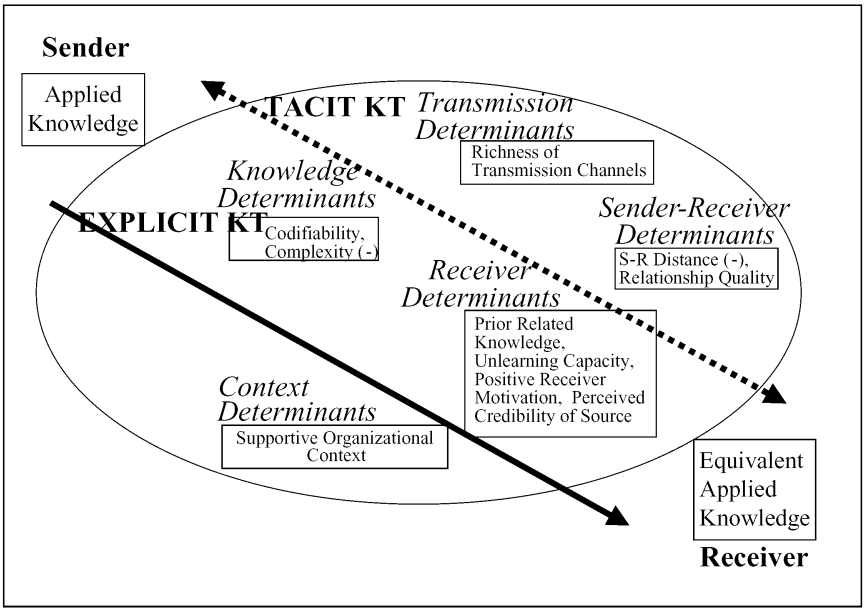


**Figure 1.** Knowledge Transfer Framework.

## 2. Methods

The validation of the KT Framework required a detailed understanding of the actual process of KT, which in turn required a qualitative case study approach. The case study approach was used to test the existing theory of the KT Framework rather than to develop theory. Our study satisfied all four of Yin's [26] criteria for using the case study method and was consistent with the previous use of case studies for KT in health services [13] and in business [27].

A single case study involving multiple embedded units [26] was used to validate the KT framework. The single case explores how Acute Myocardial Infarction (AMI) clinical practice guideline knowledge is transferred horizontally from the University of Ottawa Heart Institute (Heart Institute) to all fourteen hospitals in the Champlain District in the Province of Ontario in Canada (the embedded units) via an explicit knowledge Acute Coronary Syndrome (ACS) clinical pathway package. That is, all organizations receiving Cardiac clinical support from the Heart Institute were selected. The guideline knowledge elements were identified from AMI guideline sources [28] and validated in a line-by-line review with a Heart Institute Educator. The appropriateness of the ACS pathway package as a vehicle for AMI guideline transfer was validated by a Heart Institute cardiologist.

The key informants for this research were hospital representatives for the Cardiac Performance Project of the Champlain District Health Council with responsibility for cardiovascular disease in-hospital process of care best practice improvements. At least

one representative from each of the potential 14 receiver hospitals was selected by the study sponsor, the Heart Institute Vice-President Administration, based on these hospital's participation in the kick-off STEMI (ST-Elevated Myocardial Infarction) Care Improvement Project symposium in March 2004. Thirty-three health professionals were interviewed: 6 Physicians; 8 Managers; 7 Leads; 4 Educators; 5 Directors; 2 Coordinators; and 1 Vice-President. Data was gathered via a semi-structured interview instrument developed from previous KT research quantitative instruments [14,16,29–35]. Prior instrumentation was selected because the KT Framework determinants were already well defined thus reducing the potential of bias from selective data gathering, ensuring data collection efficiency, and enabling comparability of results [36].

Interview answers were coded using NVIVO and analysed using Site Ordered Descriptive Data and Next Step Summarizing Tables [36] structured according to the data gathering instrument. The coding involved three iterations—creation of the determinant outcome structure; coding each uncoded relevant unit into the coding structure; and searches and cross-referencing to investigate particular issues or potential findings—to address further details as the data was reviewed [36]. Selected coded elements were presented in the structure of transfer outcome, by determinant, and by determinant measure. The Next Step Summarizing Tables provided data reduction and classification to give meaning to the data [37]. An interim analysis was performed after the first three interviews as part of a cyclical and reflexive activity [37]. This analysis reoriented previous views of the types of transfers possible and their associated sense making, specifically, the Data Collection Instrument and coding structure was refined.

## 3. Findings

The Knowledge Use outcome was determined through a review of each hospital's resultant ACS Pathway Package. Documentation for each of the 14 hospitals was compared with the Heart Institute ACS Pathway Package according to the 29 clinical practice guidelines evident in the Heart Institute documentation. Each hospital's use of these guidelines was assessed as Successful (22–28 guidelines evident) or Not Successful (4–18 guidelines evident).

The research question—What are the determinants of horizontal knowledge transfer success in health services?—was addressed in two parts: a) which determinants are present for successful transfers? and b) which determinants are differentiated between KT success and KT non-success? The level of support for each determinant was assigned by a rating of the interviewee responses to the Data Collection Instrument determinant questions by three independent raters, who rated each response on a nine-point scale, with an Inter Rater Reliability of 80%. A rating of seven or higher was considered to represent support for a determinant. Applying this mechanism indicated that eight of ten determinants were supported.

Those not supported are Knowledge complexity and Richness of Transmission Channels. These results are shown in column 2 (Successful Transfer) of Table 1.

**Table 1.** Determination of Supported Framework Determinants

| Determinant | Successful Transfer | Comparative Determinant Differences | Cumulative Result |
|---|---|---|---|
| Knowledge Codifiability | Supported | | Supported |
| Knowledge Complexity | Not supported | | Not supported |
| Prior Related Knowledge | Supported | Partially Supported | Supported |
| Unlearning Capacity | Supported | | Supported |
| Positive Receiver Motivation | Supported | Supported | Supported |
| Perceived Credibility of Source | Supported | | Supported |
| Sender-Receiver Distance | Supported | | Supported |
| Relationship Quality | Supported | Partially Supported | Supported |
| Richness of Transmission Channels | Not supported | Supported | Supported |
| Supportive Organizational Context | Supported | | Supported |

The next step was to compare the relative differences between the Successful Transfer and the Non-Successful Transfer determinants. Differences in the 9-point rating of two points were recorded as Partially Supported, while differences of three or more points were recorded as Supported. This comparison is shown in column 3 of Table 1 (Comparative Determinant Differences). It indicates Successful Transfer hospitals have stronger support for three determinants, slightly stronger support for one other determinant.

These Comparative Determinant Differences did not find support for Knowledge Codifiability and Perceived Credibility of Source as both the Successful and Non-Successful transfers showed very strong support for each determinant. Comparison (column 3) is the standard approach of the KT empirical quantitative studies and it ignores both Knowledge Codifiability and Perceived Credibility of Source determinants that, with their very high level of Support, are clearly necessary for KT success. Thus, the comparative approach is not seen as sufficient measure of KT success, hence a combination of the Comparative Determinant Differences and Successful Transfer Support is proposed as a more comprehensive depiction of determinant support for KT success (column 4 of Table 1). This Cumulative Result shows support for all the determinants except Knowledge Complexity.

### *3.1. Tacit Knowledge Transfer*

To understand the transfer of tacit knowledge we used the Communications Model of Krone, Jablin and Putnam [17]. Each component in this Communications Model is shown in italics in Fig. 2 with actual elements from this research shown below each Communication Model element, e.g., Coding Scheme with HI ACS Pathway Development.

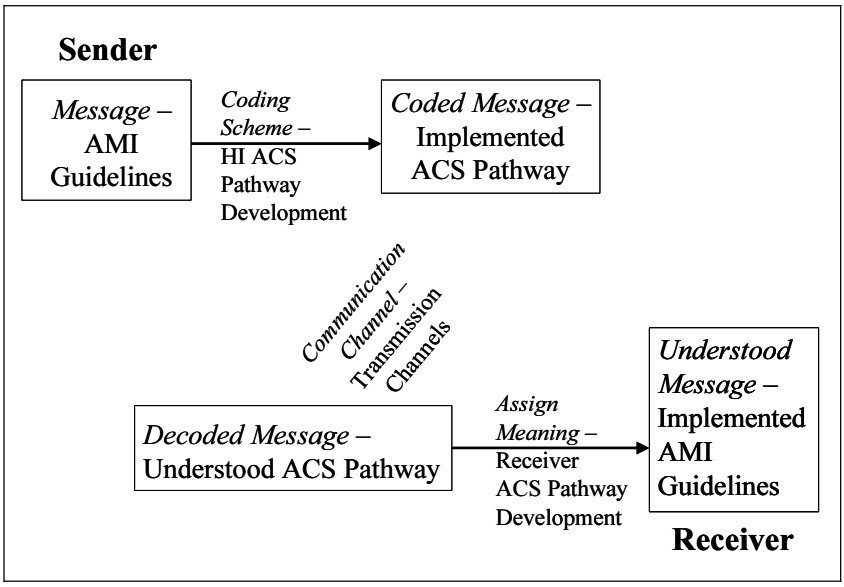


**Figure 2.** AMI Guideline Knowledge Transfer.

Table 2 describes the tacit knowledge transfer linking the Communications Model Component with the observable Explicit Element and then portraying the Tacit Knowledge Transfer Activity.

The process of Decoding Message is communicated in the words of a Receiving Hospital Manager (referenced as Hospital K):

"We took *the ACS Pathway Package* back to the Cardiac Care Committee *(a committee)* made up of two cardiologists, the manager, an educator, an intensive care area nurse, the area pharmacist, a dietician and a social worker). *The ACS Pathway Package* was put "on the table"… We had discussions around certain points. There was nothing that were "show stoppers". It was *only* little things, such as when an echogram is ordered, *or* when do we really do this?, we don't order this anymore… we came out of that meeting with everybody happy with the revised Pathway. We all had our say. We went through it, line by line, made notes on it and talked about it. We knew there were *only* minor things that we needed to fix" [italics indicate editing of comment for clarity purposes].

These necessary changes to the HI Pathway address differences in receiving hospital resources and processes, such as nursing coordinators and rehabilitation programs. When the receiving hospitals understood and internalized this explicit knowledge they created their own integration of their resource profiles and organizational processes with the AMI Guidelines and its tacit understanding, so that the implemented ACS Pathway Package became the receiving hospital's knowledge. In the case of Hospital K this understanding was facilitated by face-to-face contact with the Heart Institute,

**Table 2.** Tacit Knowledge Transfer

| Communication Model Component | Explicit Element | Tacit Knowledge Transfer Activity |
|---|---|---|
| Message | Publication of AMI Guidelines | Known/referenced basis of ACS Pathway |
| Coding Scheme | Development of Heart Institute (HI) ACS Pathway | Development infers tacit knowledge of HI resource profile and internal processes |
| Coded Message | Implementation of HI ACS Pathway | Applied tacit knowledge of HI resource profile and internal processes |
| Communication Channel | Transfer of ACS Pathway | Transfer of unique HI tacit knowledge inherent in HI ACS Pathway |
| Decoded Message | Receiver understanding of the HI ACS Pathway | Identification of HI ACS Pathway items requiring fixing |
| Assign Meaning | Receiver development of their version of the ACS Pathway | Necessary changes to HI ACS Pathway to address differences in receiving hospital resources and processes |
| Understood Message | Implementation of the receiver ACS Pathway | a) Applied tacit knowledge of receiver resource profile and internal processes;<br>b) Applied use of AMI Guideline knowledge in ACS Pathway |

sometimes considered a prerequisite for some transfers of tacit knowledge. Another hospital (Hospital H) did not have or require this face-to-face interaction.

The transfer of the profile and internal process (tacit knowledge) involved explicit knowledge, i.e., the ACS Pathway Package, acting as a trigger to the receiving hospital in the form of skills and know-how in a specific context; what Johnson-Laird [38] calls their "mental models, paradigms, schemata and beliefs that assist people in understanding their environments." The transfer of tacit knowledge was not something the Heart Institute meant to send; it was built in by the Heart Institute in their development of the ACS Pathway and then recreated by the receiving hospitals using their own, different mental models and personal know-how.

Our study used a very robust knowledge artefact to be transferred, the peer reviewed and widely accepted AMI Guidelines [39], plus a very robust measure of KT usage outcome, the easily, and unambiguously counted, the number of AMI guideline statements evident in the implemented receiving hospital ACS Pathway Package. It was also applied in an environment of health care professionals who are used to participating in new research. These three elements enabled a rigorous modelling of the KT process.

In this study we put forward an integrated business and health services empirically-grounded KT Framework consisting of ten KT determinants, a flow of unidirectional explicit knowledge and a bi-directional tacit knowledge flow. There is support for these claims in the analysis of the data arising from the case studied. It was found

for nine of these determinants and the unidirectional explicit knowledge flow, but support was not found for the two-way tacit knowledge flow, since Hospital H did not required Heart Institute interaction. Tacit knowledge was found to be an essential requirement, just as Mooradian [23] described it: the explicit ACS knowledge could not be transferred without its underlying process and resource tacit knowledge, tacit knowledge that was recreated without recognizing its specific existence. This is a new empirical finding in KT research.

This study attempted to look at both the horizontal and the vertical transfer of tacit knowledge. The vertical knowledge flow of the AMI clinical practice guidelines, related trials and resulting consensus packages, was a transfer from the researchers to the practitioners. This vertical KT was perceived as being achieved by almost all the Champlain hospitals prior to the start of this ACS Pathway transfer from the Heart Institute and was therefore not able to be measured by the KT Framework. This transfer apparently occurred over a long period of time as specific individual outcomes were consolidated into the AMI body of knowledge.

## 4. Implications for Managers

The contributions of this study include an empirically tested framework of knowledge transfer within the Health Services environment that will assist managers and potential recipients of future knowledge transfers in enabling a better and more comprehensive transfer of knowledge from the knowledge sender to the potential knowledge receivers. In particular, these managers or recipients of the transfers can use the determinant descriptions and data gathering questions to assess their KT environment and make adjustments to optimize the opportunity for KT success.

For example: in situations where the knowledge is more complex or less codified (e.g., a new organizational activity), or where the knowledge and/or culture of the knowledge sender and receiver are not similar (e.g., transfer from researchers to front-line professionals); as well as where the knowledge receiver is strongly linked to prior knowledge that this new knowledge will need to supersede (e.g., a new therapy or methodology), and where there is only a minor (or no) working relationship between sender and receiver groups, then steps will need to be taken to ensure a high level of receiver motivation in believing this new knowledge is credible and in wanting to accept and use this new knowledge, and by strengthening organizational support (e.g., funding) for the process including using richer transmission channels (e.g., having a member of the receiver team participate in the research or knowledge development activities). That is, KT environment weaknesses must be compensated for by strengthening other KT determinant areas. Health services managers can also now also investigate KT breakdowns by looking for underlying tacit knowledge embedded in sender or receiver assumptions. Thus, this study recommends the development of a rigorous KT readiness assessment tool for health services managers involved in knowledge transfers to patients, staff or other organizations.

**Table 3.** Knowledge Transfer Framework Derivation – Determinants

| Category | Determinant | Action | Empirical support |
|---|---|---|---|
| Knowledge | Tacitness | No (1) | **Simonin** [32]; **Kotabe, Martin and Domoto** [40]; **Kalling** [27]; **Edmondson et al.** [41] |
| | Knowledge Codifiability | Yes | **Kogut and Zander** [7]; **Zander and Kogut** [31]; **Grol et al.** [10]; **Hansen** [33]; Bresman, Birkinshaw, and Nobel [42]; Foy et al. [43]; **Cummings and Teng** [14]; **Edmondson et al.** [41]; **Reagans and McEvily** [44]; Williams [45] |
| | Teachability | No | **Kogut and Zander** [7]; **Zander and Kogut** [31] |
| | Knowledge Complexity | Yes | **Kogut and Zander** [7]; **Grilli and Lomas** [8]; Zander and Kogut [31]; Grol et al. [10]; **Simonin** [32]; **Hansen** [33]; Foy et al. [43]; **Cummings and Teng** [14] |
| | Causal Ambiguity | No (2) | **Szulanski** [16]; **Ko, Kirsch and King** [15] (observability measured causal ambiguity, complexity and codifiability); **Szulanski, Cappetta and Jensen** [46] |
| | Knowledge Observability | No (3) | Grilli and Lomas [8]; Zander and Kogut [31]; Grol et al.[10]; Foy et al. [43]; **Ko, Kirsch and King** [15] (as complexity, causal ambiguity) |
| | Specificity | No | Simonin [32] |
| | Trialability | No | **Grilli and Lomas** [8]; Grol et al. [10]; Foy et al. [43] |
| Sender | Positive Sender Motivation | No (4) | **Szulanski** [16] (partial support); Gupta and Govindarajan [35]; Szulanski, **Cappetta and Jensen** [46] |
| | Sender Understanding | No (4) | Sarker et al. [47]; Williams [45] |
| Receiver | Absorptive Capacity | No (5) | **Szulanski** [16]; **Mowery, Oxley and Silverman** [51]; **Gupta and Govindarajan** [35]; **George et al.** [48]; Szulanski, Cappetta and Jensen [46]; Ko, Kirsch and King [15] |
| | Retentive Capacity | No | **Szulanski** [16] |
| | Group Stability | No | **Edmondson et al.** [41] |
| | Prior Related Knowledge | Yes | **Appleyard** [49]; **Lyles and Salk** [30]; Grol et al. [10]; **Simonin** [32]; **Takeishi** [34]; **Subramaniam and Venkatraman** [29]; Foy et al. [43]; **Cummings and Teng** [14]; Sarker et al. [47]; |
| | Unlearning Capacity | Yes | **Szulanski** [16]; **Grol et al.** [10]; **Foy et al.** [43] |
| | Positive Receiver Motivation | Yes | **Szulanski** [16]; Grol et al. [10]; **Gupta and Govindarajan** [35]; Foy et al. [43]; Ko, Kirsch and King [15] (extrinsic motivation); **Ko, Kirsch and King** [15] (intrinsic motivation) |
| | Perceived Knowledge Value | No (6) | Szulanski [9, 16]; Grol et al. [10]; **Gupta and Govindarajan** [35]; Foy et al. [43]; Cummings and Teng [14]; Szulanski, Cappetta and Jensen [46] |

**Table 3.** (Continued.)

| Category | Determinant | Action | Empirical support |
|---|---|---|---|
| | Perceived Credibility of Source` | Yes | Szulanski [16]; **Grol et al.** [10]; Foy et al. [43]; **Szulanski, Cappetta and Jensen** [46]; **Ko, Kirsch and King** [15]; **Sarker et al.** [47]; **Joshi, Sarker and Sarker [50]** |
| Sender-Receiver Relationship | Sender-Receiver Distance | Yes (SR1) | Lyles and Salk [30]; **Mowery, Oxley and Silverman** [51]; **Grol et al.** [10]; **Simonin** [32]; **Hansen** [33]; Darr and Kurtzberg [52] (customer similarity); **Darr and Kurtzberg** [52] (strategic similarity); **Foy et al.** [43]; Cummings and Teng [14] (organizational distance); Ko, Kirsch and King [15]; **Sarker et al.** [47]; |
| | Link Duration | No | **Kotabe, Martin and Domoto** [40] |
| | Physical Distance | No | Darr and Kurtzberg [52] (partial); Cummings and Teng [14] |
| | Relationship Quality | Yes (SR2) | Kogut and Zander [7]; **Szulanski** [16]; Lyles and Salk [30]; **Bresman, Birkinshaw, and Nobel** [42]; Simonin [32]; **Takeishi** [34]; Crone and Roper [53]; George et al. [48]; **Subramaniam and Venkatraman** [29]; **Cummings and Teng** [14]; **Reagans and McEvily** [44]; **Ko, Kirsch and King** [15]; **Sarker et al.** [47]; **Dyer and Hatch** [54]; **Al-Alawi, Al-Marzooqi and Mohammed** [55] (trust, communication) |
| Trans-mission | Richness of Transmission Channels | Yes | **Gupta and Govindarajan** [35]; **Cummings and Teng** [14]; **Kalling** [27]; **Alawi, Al-Marzooqi and Mohammed** [55] |
| | Communication Competence | No (7) | **Davidson and McFetridge** [57]; Kogut and Zander [7]; **Reagans and McEvily** [44]; Ko, Kirsch and King [15] (communication encoding competence); **Ko, Kirsch and King** [15] (communication decoding competence); **Sarker et al.** [47]; **Joshi, Sarker and Sarker** [50] |
| Context | Supportive Organizational Context | Yes | Davidson and McFetridge [57]; Szulanski [16]; L**yles and Salk** [30] (goals and admin. support); Lyles and Salk [30] (training and tech. support); Grol et al. [10]; Simonin [32]; **Subramaniam and Venkatraman** [29]; Foy et al. [43]; Cummings and Teng [14]; **Kalling** [27]; Szulanski, Cappetta and Jensen [46]; **Alawi, Al-Marzooqi and Mohammed** [55] |

Notes: (1) Too broad a concept; (2) Assimilated into Knowledge Complexity; (3) Assimilated into Knowledge Codifiability; (4) Insufficient support; (5) – Too broad a concept; (6) Subsumed in receiver motivation; (7) Weak concept, not yet well defined.

## References

[1] Davis, D. (2005). Quality, Patient Safety and the Implementation of Best Evidence: Provinces in the Country of Knowledge Translation. Healthcare Quarterly, 8, 128-131.

[2] Boissel, J.-P., Amsallem, E., Cucherat, M., Nony, P. & Haugh, M. (2004). Bridging the Gap Between Therapeutic Research Results and Physician Prescribing Decisions: Knowledge Transfer, a Prerequisite to Knowledge Translation. European Journal of Clinical Pharmacology, 60, 609-616.

[3] Grant, R.M. (1996). Toward a Knowledge-Based Theory of the Firm. Strategic Management Journal, 17, 109-122.
[4] Spender, J.-C. & Grant, R.M. (1996). Knowledge and the Firm: Overview. Strategic Management Journal, 17, 5-9.
[5] Coakes E., Smith P. (2007). Developing Communities of Innovation by Identifying Innovation Champions, The Learning Organization, 14 (1), 74-85.
[6] Reed, R. & DeFillippi, R.J. (1990). Causal Ambiguity, Barriers to Imitation, and Sustainable Competitive Advantage. Academy of Management Review, 15, 88-102.
[7] Kogut, B. & Zander, U. (1993). Knowledge of the Firm and the Evolutionary Theory of the Multinational Corporation. Journal of International Business Studies, 24, 625-646.
[8] Grilli, R. & Lomas, J. (1994). Evaluating the Message: the Relationship Between Compliance Rate and the Subject of a Practice Guideline. Medical Care, 32, 202-213.
[9] Szulanski, G. (1996). Exploring Internal Stickiness: Impediments to the Transfer of Best Practice Within the Firm. Strategic Management Journal, 17, 27-43.
[10] Grol, R., Dalhuijsen, J., Thomas, S., Veld, C., Rutten, G. & Mokkink, H. (1998). Attributes of Clinical Guidelines That Influence Use of Guidelines in General Practice: Observational Study. British Medical Journal, 317, 858-861.
[11] Grimshaw, J. (2005). Personal communication.
[12] Orendorff, D.A. (2006). An Assessment of the State of Knowledge Transfer in Health Services: A Framework and a Health Services Case Study. Unpublished doctoral dissertation, Carleton University.
[13] Shearer, D.F. (2002). The Value of Effective Knowledge Transfer and Assimilation in New Product Development Projects: An Exploratory Study. Unpublished doctoral dissertation, Benedictine University.
[14] Cummings, J.L. & Teng, B. (2003). Transferring R&D Knowledge: The Key Factors Affecting Knowledge Transfer Success. Journal of Engineering and Technology Management, 20, 39-68.
[15] Ko, D., Kirsch, L.J. & King, W.R. (2005). Antecedents of Knowledge Transfer From Consultants to Clients in Enterprise System Implementations. MIS Quarterly, 29, 59-85.
[16] Szulanski, G. (1996). Unpacking Stickiness: An Empirical Investigation of the Barriers to Transfer of Best Practice Inside the Firm. Academy of Management Review, 17, 437-441.
[17] Krone, K.J., Jablin, F.M., & Putnam, L.L. (1987). Communication Theory and Organizational Communication. In K.J. Krone, L.L. Putnam, K.H. Roberts, & L.M. Porter (Eds.), Handbook of Organizational Communication: An Interdisciplinary Perspective. (pp. 18-40). Newbury Park, CA: Sage.
[18] Argote, L., McEvily, B. & Reagans, R. (2003). Managing Knowledge in Organizations: An Integrative Framework and Review of Emerging Themes. Management Science, 49, 571-582.
[19] Greenhalgh, T., Robert, G., MacFarlane, F., Bate, P. & Kyriakidou, O. (2004). Diffusion of Innovations in Service Organizations: Systematic Review and Recommendations. The Milbank Quarterly, 82, 1-39.
[20] Zahra, S.A., & George, G. 2002. Absorptive Capacity: A Review Reconceptualization, and Extension. Academy of Management Review, 27, 185-202.
[21] Von Krogh, G., Ichijo, K., & Nonaka, I. (2000). Enabling Knowledge Creation: How to Unlock the Mystery of Tacit Knowledge and Release the Power of Innovation. New York: Oxford University Press.
[22] Polanyi, M. (1967). The Tacit Dimension. Garden City, New York: Anchor Books.
[23] Mooradian, N. 2005. Tacit Knowledge: Philosophic Roots and Role in KM. Journal of Knowledge Management, 9, 104-113.
[24] Berta, W., Teare, G.F., Gilbert, E., Ginsburg, L.S., Lemieux-Charles, L., Davis, D., & Rappolt, S. (2005). The Contingencies of Organizational Learning in Long-Term Care: Factors That Affect Innovation Adoption. Health Care Management Review, 30, 282-292.
[25] George, G., Zahra, S.A., Wheatley, K.K. & Khan, R. (2001). The Effects of Alliance Portfolio Characteristics and Absorptive Capacity on Performance: A Study of Biotechnology Firms. Journal of High Technology Management Research, 12, 205-226.
[26] Yin, R.K. (2003). Case Study Research Design and Methods. Sage Publications.
[27] Kalling, T. (2003). Organizational-internal Transfer of Knowledge and the Role of Motivation: A Qualitative Case Study. Knowledge and Process Management, 10, 115-126.
[28] Antman, E.M., Anbe, D.T., Armstrong, P.W., Bates, E.R., Green, L.A., Hand, M., Hochman, J.S., Krumholz, H.M., Kushner, F.G., Lamas, G.A., Mullany, C.J., Ornato, J.P., Pearle, D.L., Sloan, M.A., & Smith, S.C. 2004. ACC/AHA Guidelines for the Management of Patients With ST-Elevation Myocardial Infarction: Executive Summary: A Report of the ACC/AHA Task Force on Practice Guidelines (Committee to Revise the 1999 Guidelines on the Management of Patients With Acute Myocardial Infarction). Journal of the American College of Cardiology, 44, 671-719.

[29] Subramaniam, M. & Venkatraman, N. (2001). Characteristics of Transnational New Product Development Capability: Testing the Influence of Transferring and Deploying Tacit Overseas Knowledge. Strategic Management Journal, 22, 359-378.
[30] Lyles, M.A. & Salk, J.E. (1996). Knowledge Acquisition From Foreign Parents in International Joint Ventures: An Empirical Examination in the Hungarian Context. Journal of International Business Studies, 27, 877-903.
[31] Zander, U. & Kogut, B. (1995). Knowledge and the Speed of the Transfer and Imitation of Organizational Capabilities: An Empirical Test. Organization Science, 6, 76-92.
[32] Simonin, B.L. (1999). Transfer of Marketing Know-How in International Strategic Alliances: An Empirical Investigation of the Role and Antecedents of Knowledge Ambiguity. Journal of International Business Studies, 30, 463-490.
[33] Hansen, M.T. (1999). The Search-Transfer Problem: The Role of Weak Ties in Sharing Knowledge Across Organization Subunits. Administrative Science Quarterly, 44, 82-111.
[34] Takeishi, A. (2001). Bridging Inter- and Intra-Firm Boundaries: Management of Supplier Involvement in Automobile Product Development. Strategic Management Journal, 22, 403-433.
[35] Gupta, A.K. & Govindarajan, V. (2000). Knowledge Flows Within Multinational Corporations. Strategic Management Journal, 21, 473-496.
[36] Miles, M.B. & Huberman, A.M. (1984). Qualitative Data Analysis: A Sourcebook of New Methods. Beverly Hills, CA: Sage Publications.
[37] Coffey, A., & Atkinson, P. (1996). Making Sense of Qualitative Data. Thousand Oaks, CA: Sage.
[38] Johnson-Laird, P.N. (1983). Mental Models. Cambridge: Harvard University Press.
[39] Berta, W. & Baker, R. (2004). Factors That Impact the Transfer and Retention of Best Practices for Reducing Error in Hospital. Health Care Management Review, 29, 90-97.
[40] Kotabe, M., Martin, X. & Domoto, H. (2003). Gaining From Vertical Partnerships: Knowledge Transfer, Relationship Duration, and Supplier Performance Improvement in the U.S. and Japanese Automotive Industries. Strategic Management Journal, 24, 293-316.
[41] Edmondson, A.C., Winslow, A.B., Bohmer, R.M., & Pisano, G.P. (2003). Learning How and Learning What: Effects of Tacit and Codified Knowledge on Performance Improvement Following Technology Adoption. Decision Sciences, 34, 197-223.
[42] Bresman, H., Birkinshaw, J. & Nobel, R. (1999). Knowledge Transfer in International Acquisitions. Journal of International Business Studies, 30, 439-462.
[43] Foy, R., MacLennan, G., Grimshaw, J., Penney, G., Campbell, M. & Grol, R. (2002). Attributes of Clinical Recommendations That Influence Change in Practice Following Audit and Feedback. Journal of Clinical Epidemiology, 55, 717-722.
[44] Reagans, R. & McEvily, B. (2003). Network Structure and Knowledge Transfer: The Effects of Cohesion and Range. Administrative Science Quarterly, 48, 240-267.
[45] Williams, C. (2007). Transfer in Context: Replication and Adaptation in Knowledge Transfer Relationships. Strategic Management Journal, 28, 867-889.
[46] Szulanski, G. Cappetta, R. & Jensen, R. (2004). When and How Trustworthiness Matters: Knowledge transfer and the Moderating Effect of Causal Ambiguity. Organization Science, 15, 600-613.
[47] Sarker, S., Sarker, S., Nicholson, D.B. & Joshi, K.D. (2005). Knowledge Transfer in Virtual Systems Development Teams: An Exploratory Study of Four Key Enablers. IEEE Transactions of Professional Communication, 48, 201-218.
[48] George, G., Zahra, S.A., Wheatley, K.K. & Khan, R. (2001). The Effects of Alliance Portfolio Characteristics and Absorptive Capacity on Performance: A Study of Biotechnology Firms. Journal of High Technology Management Research, 12, 205-226.
[49] Appleyard, M.M. (1996). How Does Knowledge Flow? Interfirm Patterns in the Semiconductor Industry. Strategic Management Journal, 17, 137-154.
[50] Joshi, K, Sarker S. & Sarker S. (2007). Knowledge Transfer within Information Systems Development Teams: Examining the Role of Knowledge Source Attributes. Decision Support Systems, 43, 322-335.
[51] Mowery, D.C., Oxley, J.E. & Silverman, B.S. (1996). Strategic Alliances and Interfirm Knowledge Transfer. Strategic Management Journal, 17, 77-91.
[52] Darr, E.D. & Kurtzberg, T. (2000). An Investigation of Partner Similarity Dimensions on Knowledge Transfer. Organizational Behavior and Human Decision Processes, 82, 28-44.
[53] Crone, M. & Roper, S. (2001). Local Learning from Multinational Plants: Knowledge Transfers in the Supply Chain. Regional Studies, 35, 535-548.

[54] Dyer, J. & Hatch, N. (2006). Relation-Specific Capabilities and Barriers to Knowledge Transfers: Creating Advantage Through Network Relationships. Strategic Management Journal, 27, 701-719.
[55] Al-Alawi, A., Al-Marzooqi, N. & Mohammed, Y. (2007). Organizational Culture and Knowledge Sharing: Critical Success Factors. Journal of Knowledge Management, 11, 22-42.
[56] Davidson, W.H. & McFetridge, D.G. (1985). Key Characteristics in the Choice of International Technology Transfer Mode. Journal of International Business Studies, 16, 5-21.

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# Knowledge Management Model for Teleconsulting in Telemedicine

Lilia Edith Aparicio Pico[a,1], Orlando Rodriguez Cuenca[a], Daniel José Salas Alvarez[b]
Piere Augusto Peña Salgado[b]
[a] *Distrital University Francisco José de Caldas, Colombia*
[b] *Córdoba University, Colombia*

**Abstract.** The present article shows a study about requirements for teleconsulting in a telemedicine solution in order to create a knowledge management system. Several concepts have been found related to the term teleconsulting in telemedicine which will serve to clear up their corresponding applications, potentialities, and scope. Afterwards, different theories about the art state in knowledge management have been considered by exploring methodologies and architectures to establish the trends of knowledge management and the possibilities of using them in teleconsulting. Furthermore, local and international experiences have been examined to assess knowledge management systems focused on telemedicine. The objective of this study is to obtain a model for developing teleconsulting systems in Colombia because we have many health-information management systems but they don't offer telemedicine services for remote areas. In Colombia there are many people in rural areas with different necessities and they don't have medicine services, teleconsulting will be a good solution to this problem. Lastly, a model of a knowledge system is proposed for teleconsulting in telemedicine. The model has philosophical principles and architecture that shows the fundamental layers for its development.

Keywords. Telemedicine, Teleconsulting, Knowledge Management, Organizational Model, Technological Architecture

## Introduction

Teleconsulting has been defined by diverse authors in several ways. These can be seen as an approach to the term keeping in mind the environment of telemedicine: "An Opinion or a piece of advice that is requested about a something", "Search of data that is using books, newspapers, files, etc., to be informed on a matter", "Assessment or inspection that the doctor makes to an ill person", "Local personal service given by doctors to patients " and "Conference among professionals to solve something ". All the previous concepts contribute the teleconsulting definition.

Let's see some of the descriptions that diverse authors have outlined for Teleconsulting. The American Telemedicine Association (ATA) [1] defines teleconsulting as: service that uses the telecommunications to provide medical data, which can be audio, photograph or videos, between a patient and health care professional to de in assistance use it in attendance, diagnostic or a treatment plan.

[1] Corresponding Autor: Distrital University, Francisco José de Caldas, Bogotá Colombia, 7 Avenue 40-53 level 4, E-mail: medicina@udistrital.edu.co

These could be originated from a remote clinic to an office using a connection of direct transmission that can include communications on the Web.

Likewise, a more specified definition [2] says that teleconsulting (e-consultation) is not a very expensive alternative that contains multiple clinical criteria within same group of specialists. This technology allows the rural areas, urban areas is, by far, one of the most frequently used procedures in telemedicine, prisons and other areas to receive medical services that otherwise would not be available. Another approach is [3] teleconsulting is frequents of the procedures in telemedicine. We can find another possible definition [4] when a medical consultation is replaced by a remote assisted electronic consultation. Given the above-mentioned there is no doubt to assure that teleconsulting is a telemedicine service that uses information and telecommunication technologies to carry out medical consultations among patients and doctors. Teleconsulting has existed almost since the appearance of the Internet. In the United Kingdom for example in 2003 there was a penetration of internet in 48% of the households while in the United States it reached 60% that same year [5], people being and not being patients found useful information about illnesses finding articles and stories about these illnesses and many times they could discover on-line satisfactory answers. It makes us wonder about the question: is it necessary to consult with a physician nowadays, especially in a country like Colombia where the level of self-medication of the population is 47% according to a study carried out by The Antioquia University - Colombia [6]. These figures are obtained using search engines such as "GOOGLE". This is why it comes as necessary to create a knowledge management system.

## 1. Knowledge Management Systems

A knowledge management system is defined as "the process of administrating knowledge of all kinds continually to satisfy present and future necessities, to identify and to exploit resources of knowledge and to develop new opportunities." [7]. Another approach to this concept affirms that "Knowledge management wraps the identification and analysis of knowledge available as it is required, also, controls the piles of information to develop active knowledge with the purpose of reaching organizational objectives" [8], additionally, it applies to the information that is generated in a telemedicine system and in teleconsulting as a component of the same system.

### *1.1. Knowledge management methodologies*

There is a methodology for implementing a knowledge management system. The methodologies and architectures that have been refined and widely accepted by the scientific community to be a standard are following.

#### *1.1.1. Tiwana methodology*

This methodology is proposed by Amrit Tiwana and adapted by Coviello and others [9], which has 4 phases and 10 stages (see Figure 2).

| |
|---|
| Phase 1: Evaluation of the infrastructure |
| 1) Analysis of the existent infrastructure |
| 2) Alignment of knowledge management and the business strategy |
| Phase 2: Analysis, Design and Development of the System of MK |
| 1) Design of the architecture of knowledge management and integration of the existent infrastructure. |
| 2) Audit to Knowledge Resources and Systems already existent |
| 3) Design of a knowledge management Team |
| 4) Creation of a knowledge management project |
| 5) Development of a knowledge management system |
| Phase 3: System Deployment |
| 6) Deploying the system, using Methodology Incremental Handling of Results (*RDI)* |
| 7) Change of management, Culture and Structures |
| Phase 4: Evaluation |
| 8) Evaluation of the yield, Menstruation of the ROI, and incremental refinement of the system of knowledge management. |

**Figure 1. .** Methodology of Knowledge Management: Tiwana Source: Adapted by Coviello and others of Tiwana (2002, pp. 64)

### *1.1.2. EKMF methodology*

The methodology of the EKMF project (European Knowledge Management Forum) [10] is an initial proposal to a possible standard methodology for the implementation of knowledge management, which is structured in two levels.

#### *1.1.2.1. Level 1: General implementation of Knowledge Management*

This level is compound by 6 phases and 16 stages (see Figure 2.)

#### *1.1.2.2. Level 2: Implementation of a Knowledge Management Pilot Project.*

It refers to knowledge management for specific problems and it can turn as a part of the general methodology (see Figure 3).

### *1.1.3. Methodological application of knowledge management*

Structurally, the methodology is composed by phases that pick up the initial position of a situation, with the whole chain of stocks (piles of information) that are necessarily involved until reaching the new wanted situation. These phases ease the development of a procedure to be modified in such a way that they perform together as part of the system like independent subsystems that cover their own performance environment, in the course of their full integration [18].

| Phases | Stages | |
|---|---|---|
| Phase 1: Knowledge | 1 | Interest in knowledge management and its benefits |
| | 2 | Involving top management organization |
| Fase 2: Initial valuation | 3 | Team Work |
| | 4 | Existent infrastructures |
| | 5 | Economic compatibility |
| | 6 | Knowledge management and sources of business |
| | 7 | Estimates |
| Fase 3: Iniciativas Piloto | 8 | Selecting alternatives to be developed |
| | 9 | Designing and launching a pilot project on knowledge management |
| Fase 4: Expansion | 10 | Current state of knowledge management |
| | 11 | Expansion possibilities |
| | 12 | Personalization and application of knowledge management |
| | 13 | Introducing the expansion of the knowledge management project. |
| Fase 5: Maturity | 14 | Strategies and organizational structures |
| Fase 6: Continuous improvement | 15 | Results of knowledge management |
| | 16 | Improvement |

**Figure 2.** General implementation of knowledge management: EKMF Source: Project EKMF, Coviello and others (2002, pp. 82)

The phases are formed by a group of activities that should be carried out when each phase is executed. These activities can be separated by turn and task and their structure has been outlined with a group-concurrent development, which provides a saving in terms of execution and cost. The task is the basic unit. It brings its own content and some stocks (piles of information) to be used. In a general way, each task can be structured by: Available Sources of information, steps or processes to be carried out or factors that can have incidence in their execution, support tools, products or results and advice to facilitate the execution of each task.

In turn, the methodology emphasizes a complementary balance that represents a recurrent infinite development among its different phases and activities that finally leads to the improvement through a repetitive and incremental process. It is incremental because new plans can be added to reach the goal. It is robust and stable since, while maintaining the goal, it keeps the same goal and modifies itself. This would admit changes in the behavior.

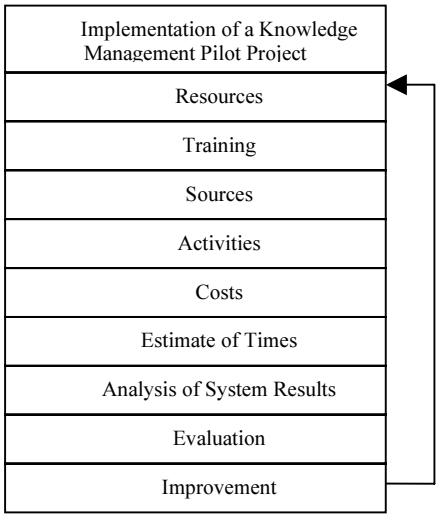


**Figure 3.** Implementation of Knowledge Management Project Pilot: EKMF Source: Project EKMF, Coviello and other (2002, pp. 83)

### *1.2. Knowledge management architecture*

There are diverse technological focuses to support the knowledge management architecture in an organization. Therefore, they have been accepted by the scientific community. A good example is: Ovum, Tiwana and technological Integration (Kerschberg)

#### *1.2.1. Ovum Architecture*

Ovum has developed a model of knowledge management architecture which is shown in Figure 4. Its main components are: the repository of knowledge, the map of knowledge, the services of collaboration, the discovery services and the portal of knowledge.

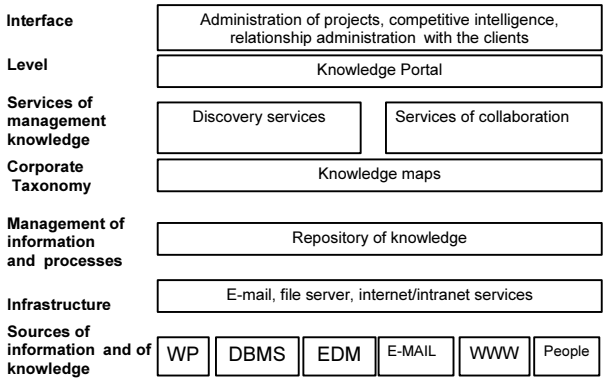


**Figure 4.** Architecture of Management knowledge Model Ovum. Source: Ovum Ltda. Woods (1998)

*1.2.2. Tiwana Architecture*

Tiwana gives knowledge in seven layers integrated by using the Web [9], (see Figure 5).

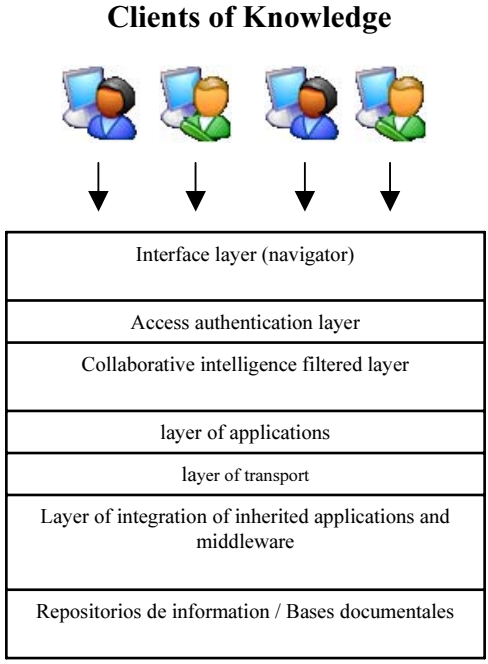


**Figure 5.** Architecture of Tiwana. Source: Amrit Tiwana (2002, pp. 127)

## 2. Cases of Study

Some telemedicine systems present international levels such as the pattern of Telefonica (Spain) model FEPAFEM (Pan-American Federation of Association is of Ability it is and Schools of Medicine) and one at national levels such as the one at Cauca University

*2.1. University of Regensburg Medical Center Model*

This model explains the necessary components to carry out a telemedicine system. It offers rehabilitation, security, diagnose. Among the possible subsystems left are: teledermatology, teleradiology, teleconsulting, telediagnostic, etc. [11].

### *2.2. Action and—Health Program*

The program is compound by different components: the operating theatres, the classrooms and auditories [12]. The services are:

- Teleconsulting
- Differed Consults
- Second opinion.
- Team Work among health professionals
- Tele-education.
- Databases
- Information to the citizens
- Telemedical and sanitary attendance

All these elements show the repositories (database and clients) being processed, hence, they make up the whole information medical telemedicine system.

### *2.3. Telefónica Company Model*

In the administration service of Medical Images, Telefónica is responsible for all broadband communications, the infrastructure process, storage, capture of medical images (x-ray, retinographies, etc.), and so it charges the client for the service (storage or image consultation). This has been developed jointly with General Electric [13].

### *2.4. The Pan-American Federation of Schools of Medicine Association Model (FEPAFEM)*

This model is designed to improve the clinical coordination and therapy and to promote team work among doctors of primary attention and specialists [14].

### *2.5. Applications of Telecommunications in Health in the Andean Sub region Model (Cauca University - Colombia)*

The Model has applications in telemedicine networks with many remotely-connected users, which can be located in rural or urban remote points. Here are four main components: Hospital Information System HIS (Hospital Information System), Acquisition and Digitization Teams, Administration and Storage Clients, and Reading System. This architectures can work in two ways: on-line through a client's Web, or store-and-forward (storage and shipment), through a synchronized office of clients and information [15].

The first case is used by the Applications Supplying Service calls ASP (Application Service Provider) that consist of providing on-line applications through Web sites, without the user of the application having to buy and install a program, which makes the cost of the software lower, since users only pay a lease. It only requires an internet browser and a connection to the Web to be permanently on-line.

In the second case an on-line connection is not required. The user can work disconnected from the net (off-line), but in this case users require an application installed in their PC with a local database. It only needs a connection to the local network at the moment of exchanging information with clients.

### *2.6. Management System for Public Hospitals in Bogotá City*

This solution includes telecommunication platforms and information systems to show specialists how to process information about primary problems in telemedicine networks. The platform of communications already foreseen is being offered by The Bogotá's Telecommunications Company (ETB). It is a system for attending references and distributed consultation services at Hospitals in Bogotá City [16]

### *2.7. Telecardiology System in Colombia*

The telecardiology system was developed using a layered architecture, where each stage on the transmission has its dual stage in the receiver. The acquisition module takes up an ECG signal and storages it in a medical record sending a diagnosis together with other patterns within the same local teleconsulting service.[17] , [18]

## 3. Knowledge Management Model for Teleconsulting in Telemedicine

There is a lack of knowledge management systems for teleconsulting in telemedicine. This model is based on elements such as ubiquity principles, cost, the use of specialized human resources, communication technologies, and positive knowledge exploitation. In order to implement this model the structures and the technological layers should be kept in mind.

### *3.1. Principles of the proposed pattern*

- Ubiquity: The Information and Knowledge Technologies (TIC´s) provide us with advantages. It is not necessary to be present with doctors to use health services. It is possible to take these services through the internet and other networks.
- Cost: It is cheaper to use information and knowledge information systems than using direct services with doctors. Doctors can offer their services through the teleconsulting system
- Communications Technology: There are many networks that offer communication services. It is important to use these services for delivering knowledge.
- Positive exploitation of knowledge: Knowledge will go growing, and it will be of better use for the different clients of knowledge.

### *3.2. Organizational model*

It represents the main components of the pattern in Figure 6. There are primary nodes (non-expert clients of knowledge) conformed by actors that need to acquire advanced knowledge or a second opinion. The technological agents in charge of mediating between the primary nodes and the specialized ones have the purpose of deciding whether the consultation made by a primary node can be solved with the repository of knowledge or whether it is necessary to go to a specialized node. The repository of knowledge stores the whole experience when exchanging knowledge among the primary specialized nodes aiming to reuse it. Ultimately, the specialized nodes are the

group of people who possess knowledge at a superior level at the service of the other people in the primary nodes.

### *3.3. Technological architecture*

The technological architecture is a combination of the Kerschberg architecture mentioned above and the patron MVC of Buschmann 1980 [19].

It has four components (see Figure 6). It would be like saying that a new knowledge management layer has been added to the architecture of Kerschberg. It has been divided into two layers. These layers called components in the architecture technological proposal are detailed as follows:

Component of view: The component of view takes over the visual representation of knowledge and of the information. It has an interface for users of the well-known primary nodes known as "Simple User Interface" and another for users of the well-known specialized nodes known as "Expert User Interface." Basically, they communicate through the Internet using the following Layer.

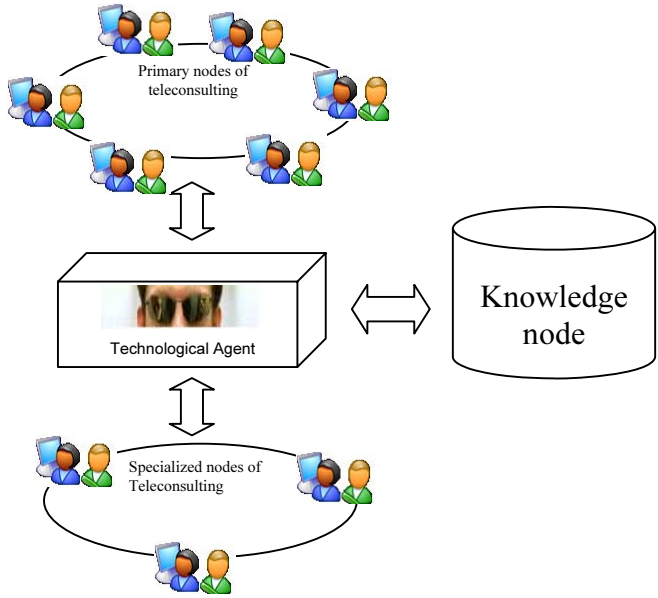


**Figure 6.** It structures the pattern organizational Source: Own elaboration

Component Controller: it takes all users´ requests and coordinates the answers appropriately. This component is responsible for capturing the interaction of all application services. The controller authenticates the users and evaluates their necessities of information knowledge, a middleware of HL7 (Health Level Seven level protocol 7 [20]) that formats the information from and towards the repository of knowledge.

Component of Repositories: They store knowledge that has been mined by a middleware of knowledge mining; it is an extract of knowledge from following layers

to facilitate the work for the technological agent, it stores the experience in the knowledge exchange between the primary nodes and the specialized nodes.

Component of sources: This component refers to all the explicit and potential sources that generate knowledge, among others are (databases, documental databases, database of means, external sources, etc.) (See Figure 7).

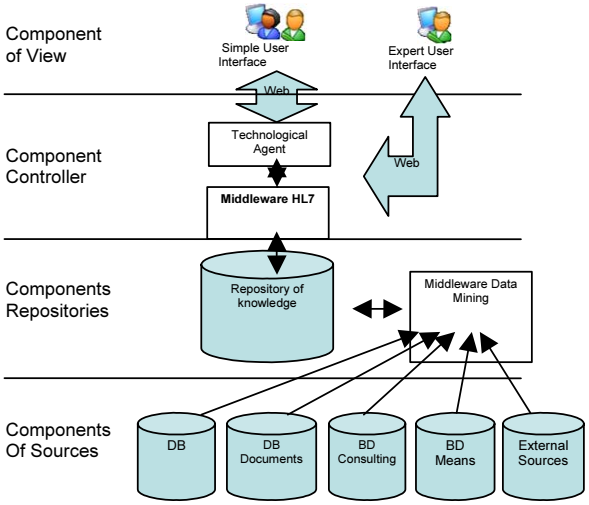


**Figure 7.** Structures. of the Architecture Technological. Source: Own elaboration

## 4. Summary

The knowledge management system can be used to strengthen simple systems of information in diverse areas of application. In this document, we have attempted to create an example of it by formulating a model of knowledge management for a teleconsulting system in telemedicine combining theories, models and architectures of knowledge management; especially with a computer case, generating some principles, organizational structures and an architecture technological matter.

Apart from this, we can assert that the proposed pattern of a knowledge management model for the implementation of teleconsulting in telemedicine will serve as a conceptual guide for works that require the development and implementation of information systems in telemedicine and systems of knowledge management in telemedicine. In order to make a decision for teleconsulting in Colombia, it is possible to analyze the model to connecting Management Systems in Bogotá and Cauca in order to give services between Bogotá and other rural places. This would be our next research.

## References

[1] ATA: American Telemedicine Assotiation <URL:http://www.atmeda.org/index.asp>
[2] TAN Jhoshep, E-health care information system, Willey, 2005, pp - 169

[3] NORRIS C, Essential of telemedicine and telecare, Willey & Sons, 2001, pp 20.
[4] TAKEDA Hiroshi, High quality image oriented telemedicine with multi-media, International Journal of Medical Informatics 55 (1999), pp 23-3.
[5] SULLIVAN Frank and WYATT Jeremy C, Is a consultation needed, BMJ Journals 2005;331; pp 625-627
[6] TOBON Flor, Estudio sobre automedicación en la Universidad de Antioquia, Medellín, Colombia, IATREIA Vol. 15, No.4, 2002.
[7] QUINTAS, Paul; LEFRERE, Paul; JONES, Geoff, Knowledge Management: a Strategic Agenda, Long Range Planning, Vol. 30, No. 3, pp. 385 a 391, 1997, Elsevier Science Ltd.
[8] MACINTOSH, Ann, Position Paper on Knowledge Management , Artifitial Intelligence Applications Institute, University of Edinburgh, Matzo, 1997.
[9] TIWANA, Amrit, The Knowledge Management Toolkit, Prentice Hall, 2002, pp. 64
[10] THE EUROPEAN KM Forum Consortium, IST Project No 2000-26393
[11] Model University of Regensburg Medical Center <URL:http://www.tmf-ev.de/site/DE/int/AG/DS/Projekte/Sicherheitskonzepte Dokumente/14_Blobel_Zukuenftige_Systemarchitekturen.pdf?PHPSESSID=8c8662ab1 16a80798286a7cb9c8e136c>
[12] Model of "Secretaria de Salud de México" <URL:http://www.salud.gov.mx/unidades/cenetec/archivoscenetec/pdf/CENETEC_Telemedicina.pdf>
[13] Model of Telefónica-España. <URL: http://empresas.telefonica.es/documentación/presencia_externa/GestCorpDeLaImgenMedica_JCMDT .pdf>
[14] Proyect S.O.S, Telemedicine for Venezuela <URL:http://www.fepafempafams.orgdocuments/seminario_mayo2006/telemedicina_ucv.pdf>
[15] Model Universidad del Cauca Colombia <URL: http://www.comunidadandina.org/telec/Documentos/Telecomunicaciones_salud.pdf>
[16] APARICIO L.E. Rodríguez O. "Information System for Health Management of Patients on Public Hospitals in Bogotá City". Technology and Health Care Volume 12, Number 5, 2004 ISSN 0928-7329
[17] APARICIO L.E. Rodriguez O. Improving Public health Through the Internet, JMIR Pubications "Telecardiology system using Internet and Picosatellite Connections" Vol. 1 Octubre 2006, ISSN 1-897041-50-0.
[18] APARICIO l.E, Arco P. Telecardiology Data Compression and Error Control System, Proceedings of IOMP Internacional organization of Medical Physics Volume 1.
[19] BUSCHMANN, F. et al, Pattern-Oriented Software Architecture, Vol. 1: System of patterns, John Wiley & Son Ltda., 1997.
[20] HL7 Organization <URL: http://www.hl7.org>

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# InWiM: Knowledge Management for Insurance Medicine

Juerg P. Bleuer[a,1], Kurt Bösch[b], Christian A. Ludwig[b]
[a] *Healthevidence GmbH, Berne, Switzerland*
[b] *Suva, Lucerne, Switzerland*

**Abstract.** Suva (Swiss National Accident Insurance Fund) is the most important carrier of obligatory accident insurance in Switzerland. Its services not only comprise insurance but also prevention, case management and rehabilitation. Suva's medical division supports doctors in stationary and ambulatory care with comprehensive case management and with conciliar advice. Two Suva clinics provide stationary rehabilitation. Medicine in general, including insurance medicine, faces the problem of a diversity of opinions about the facts of a case. One of the reasons is a diversity of knowledge. This is the reason why Suva initiated a knowledge management project called InWiM. "InWiM" is the acronym for "Integrierte Wissensbasen der Medizin" which can be translated as "Integrated Knowledge Bases in Medicine". The project is part of an ISO 9001 certification program and comprises the definition and documentation of all processes in the field of knowledge management as well as the development of the underlying ITC infrastructure. The knowledge representation model used for the ICT implementation considers knowledge as a multidimensional network of interlinked units of information. In contrast to the hyperlink technology in the World Wide Web, links between items are bidirectional: the target knows the source of the link. Links are therefore called cross-links. The model allows annotation for the narrative description of the nature of the units of information (e.g. documents) and the cross-links as well. Information retrieval is achieved by means of a full implementation of the MeSH Index, the thesaurus of the United States National Library of Medicine (NLM). As far as the authors are aware, InWiM is currently the only implementation worldwide – with the exception of the NLM and its national representatives - which supports all MeSH features for in-house retrieval.

**Keywords:** Knowledge management, knowledge representation, information retrieval, MESH Index

## Introduction

Suva (Swiss National Accident Insurance Fund) is the most important carrier of obligatory accident insurance in Switzerland. It is an independent, non-profit-making company under public law and mainly insures companies in the secondary business sector, i.e. industrial, trading and commercial enterprises.

Suva is more than just an insurance company. Its services comprise not only insurance but also prevention, case management and rehabilitation. Prevention focuses

[1] Corresponding author: Juerg P. Bleuer, MD, MPH, Healthevidence GmbH, P.O. Box 6551, CH-3001 Berne, Switzerland; Email: bleuer@healthevidence.ch

on occupational and leisure-time safety as well. In order to ensure the most effective treatment for all patients, the Suva's medical division supports doctors working in inpatient and outpatient care with comprehensive case management and with conciliar advice. Two Suva clinics provide inpatient rehabilitation.

Medicine often faces the problem of a diversity of opinions about the facts of a case. Medicine is an action science. The coexistence of doctrines therefore results in insecurity about the appropriateness of any actions and concerns doctors and patients as well. In the late 1970s, a working group at McMaster University, Hamilton, Ontario, started to develop new concepts for clinical decisions. Later, this work emerged in a worldwide movement, called Evidence-based Medicine (EBM) [1]. David Sackett defined evidence-based medicine as "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" [2].

In insurance medicine, divergent opinions not only affect curative procedures but they also bear the risk of different decisions about financial aspects, e.g. whether a health problem is covered by the accident insurance or not. Patients perceive divergent decisions in this field as injustice and lawsuits may be the consequence. From an ethical point of view, such divergence in verdicts is unacceptable.

Before you can make "explicit and judicious use of current best evidence", you have to know about it, you are in need of the current best knowledge. One of the reasons for the diversity of opinions is a diversity of knowledge. Assuring the same "current best" knowledge for all doctors was therefore the main goal for a knowledge management project called "InWiM". "InWiM" is the acronym for "Integrierte Wissensbasen der Medizin", which can be translated as "Integrated Knowledge Bases in Medicine". The project is part of an ISO 9001 certification program and comprises the definition and documentation of all processes in the field of knowledge management as well as the development of the underlying ITC infrastructure.

## 1. Terminology

In everyday language, people often do not differentiate between the terms "data", "information" and "knowledge" and many definitions can be found in the literature. This paper adopts the definitions of Rehäuser und Krcmar [3]. According to them, the term "data" refers to symbols that represent a fact or statement of event without any relation to other data. The term "information" is used for data in context. "Knowledge" is achieved through the process of linking pieces of information together based on logical thinking. Schreyögg and Geiger call this an "approach to knowledge inspired by information theory" [4].

In general, knowledge management systems do not handle pure data. At the time when data is subject to knowledge management processes, it has already been put in some sort of context. Therefore, it is more appropriate to use the term "information". In practice, there is no strict border between information and knowledge. It is useful to consider the way from information to knowledge as a continuum. The following example may illustrate this: one single scientific publication will give the reader information about a specific issue. If he considers several studies and puts the results and conclusions in relation, he will gather more and more knowledge about the subject of these studies. Eventually some authors will write reviews about studies and someday, somebody will summarize all the publications including the primary, secondary and tertiary literature. Along the way, information is transformed into

knowledge. Provided that the reviews are properly done, the knowledge gets sounder and sounder with each review.

It may be helpful in this context to distinguish the term "knowledge" as we understand it here from the meaning in everyday language, where knowledge has the connotation of "truth" which distinguishes it from "belief". When we speak of knowledge in this article, nothing is said about its correctness. Knowledge and information may be wrong or right. In order to point out that some knowledge is reliable, one may speak of well-established knowledge. Evidence-Based Medicine goes further and denotes the reliability with levels of evidence and grades of recommendation respectively [5]. E.g. evidence is considered to be sound if it is supported by multiple studies of high methodological quality [6].

## 2. The knowledge management model used for InWiM

Everything in the InWiM Project turns around the concept of "knowledge" understood as a result of linking pieces of information together and therefore as an outcome of brain work. This implies that knowledge is subjective: Personal knowledge can be seen as an individual network of interlinked pieces of information. It is important to see that such a personal knowledge network is multidimensional. The latter results from the fact that information can be interlinked from different points of view. The following example may illustrate this: Let us assume that we have some studies investigating the effect of different surgical techniques in joint surgery. It will make sense to link all the papers that report on the same technique on different joints as well as those which investigate different techniques at the same joint. Additional links may be useful to denote methodological aspects, demographical issues, etc. Fig. 1 illustrates how units of information (e.g. publications of studies) are linked together in multiple dimensions. In contrast to the hyperlink technology in the World Wide Web, all links are bidirectional: the target knows the source of the links. The links are therefore called cross-links.

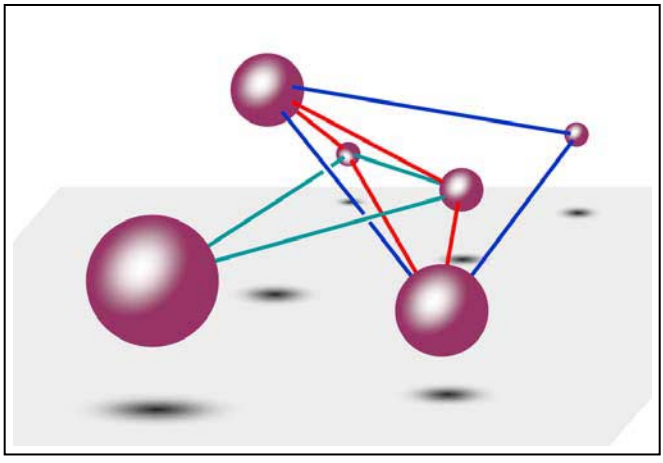

**Figure 1.** Graphic illustration of a multidimensional knowledge network: items of information (e.g. publications of studies) are drawn as balls, lines with the same color represent cross-links of the same dimension.

The "inspired by information theory" understanding of knowledge [4], implies that knowledge always has to be seen in context [3, 7, 8]. A model, which claims to be able to depict knowledge as a network of cross-linked units of information must therefore include meta-information not only for the units of information (e.g. documents) but also for each crosslink. Meta-information not only includes the name of the author, date, version, etc. but also freetext annotations, which allow for a narrative description of the point of view under which a specific cross-link was established.

If we adopt the model that personal knowledge can be seen as a multidimensional network of information, corporate knowledge can be regarded as the synthesis of all personal knowledge networks in an institution: This means that each user can store his units of information (e.g. documents) and that these documents are visible for all other users. Each user can then construct as many cross-links as needed which include not only his own but also units of information from other users. Annotations can be added to cross-links and units of information as well: the number of annotations is not restricted, neither per document nor per crosslink. All annotations are visible not only to the author but to all users.

## 3. Information retrieval

If corporate knowledge is the synthesis of all dimensions of each personal knowledge web, surfing through the cross-links will help to retrieve the desired knowledge and/or information. However, the question remains where to start or – put another way – how to find the appropriate access point.

InWiM provides the powerful tool of MeSH Index (Medical Subject Headings), the thesaurus of the United States National Library of Medicine (NLM) for this purpose. The MeSH Index consists of terms naming descriptors in a hierarchical structure. In 2008, there are 24,767 descriptors in the MeSH thesaurus. Over 97,000 entry terms assist in finding the appropriate MeSH Heading by entering the usual medical term [8]. As an example, "Vitamin C" returns the MeSH Heading "Ascorbic Acid." InWiM supports all the features of MeSH including subheadings and limits. It allows users to search the in-house document repository as well as access the online literature service of the NLM (www.pubmed.org) through the same graphical user interface. As far as the authors are aware, InWiM is currently the only implementation worldwide – except for the NLM and its national representatives - which supports all MeSH features for in-house retrieval.

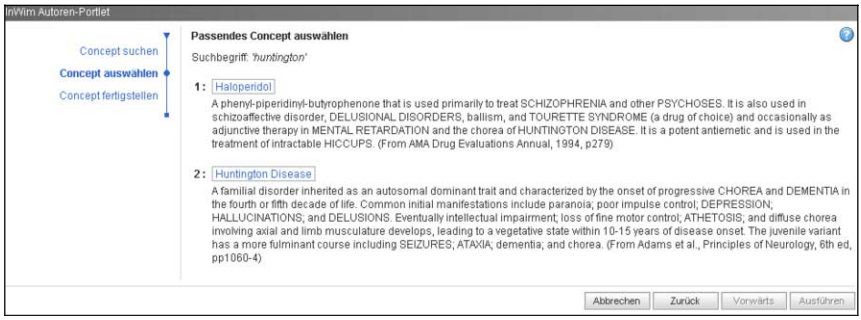


**Figure 2.** MeSH search in InWiM: Search result for "Huntington".

Searching by MeSH terms is supported by a wizard (see Fig. 2) to make the use of InWiM easy. A similar wizard assists the user to index documents at check-in.

## 4. Transferring the model to ITC

In order to depict the model outlined in the preceding paragraph, the InWiM application was designed to provide the following core features:

- Document storage: Each document is considered as an item of information. Documents can be text files but also multimedia documents in different technical formats. Documents are visible to all users. A version control is provided.
- Cross-links: A cross-link can be regarded as a network, tying any number of documents together. Being part of a specific crosslink, each document shows all the other documents of the particular crosslink thus providing easy access to them.
- Annotations: Users can add annotations to documents and cross-links as well. The number of annotations is not restricted. Annotations are visible to all users.

InWim is based on the Enterprise Content Management System FileNet P8. An Oracle database holds the MeSH Index. BEA portal (WLP) provides the graphical user interface by means of a portlet.

InWiM is now at the pilot-project stage. The InWiM application is rolled out in Version 1. Current users include doctors and other healthcare professionals at Suva. It is planned to use InWiM not only as an intranet application but to open it for access over the internet in order to support professionals in inpatient and outpatient healthcare. Later, patients will also have access, thus making insurance medicine transparent and decisions understandable for lay persons.

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## References

[1] Guyatt G, Cairns J, Churchill D, et al. Evidence-Based Medicine Working Group. Evidence-based medicine. A new approach to teaching the practice of medicine. JAMA 1992;268:2420-5.

[2] Sackett, DL, Rosenberg WMC, Gray JAM, Haynes RB, Richardson WS. Evidence-based medicine: what it is and what it isn't. BMJ 1996;312:71-2.
[3] Rehäuser J, Krcmar H, Schreyögg G. Wissensmanagement in Unternehmen. Walter de Gruyter: Berlin 1996.
[4] Schreyögg G, Geiger D. Wenn alles Wissen ist, ist Wissen am Ende Nichts?! Vorschläge zur Neuorientierung des Wissensmanagements. In: Zeuch A (Ed.). Management von Nichtwissen im Unternehmen. Carl Auer 2007. 69 – 89.
[5] Canadian Task Force on the Periodic Health Examination. The periodic health examination. CMAJ 1979;121:1193-254.
[6] Oxford Centre for Evidence-based Medicine. Levels of Evidence. http://www.cebm.net/index.aspx?o=1025.
[7[ Steinmüller W. Informationstechnologie und Gesellschaft: Einführung in die Angewandte Informatik. Wissenschaftliche Buchgesellschaft: Darmstadt 1993.
[8] von Krogh G, Koehne M. Der Wissenstransfer in Unternehmen: Phasen des Wissenstransfers und wichtige Einflussfaktoren. Die Unternehmung 1998;5:235-52.
[9] United States National Library of Medicine. Medical Subject Headings (MeSH®). http://www.nlm.nih.gov/pubs/factsheets/mesh.html.

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# Realising the Knowledge Spiral in Healthcare: the role of Data Mining and Knowledge Management

Nilmini WICKRAMASINGHE PhD, MBA [a], Rajeev K BALI PhD, MSc [b,c]
M Chris GIBBONS MD, MPH [d], Jonathan Schaffer MD, MBA [e]

[a] *Center for the Management of Medical Technology,*
*Stuart Graduate School of Business, Illinois Institute of Technology, Chicago, USA*
[b] *Knowledge Management for Healthcare (KARMAH) research subgroup,*
[c] *Biomedical Computing and Engineering Technologies Applied Research Group (BIOCORE), Coventry University, UK*
[d] *Johns Hopkins Urban Health Institute,*
*Johns Hopkins Medical Institutions, Baltimore, USA*
[e] *The Cleveland Clinic, Cleveland, USA*

**Abstract.** Knowledge Management (KM) is an emerging business approach aimed at solving current problems such as competitiveness and the need to innovate which are faced by businesses today. The premise for the need for KM is based on a paradigm shift in the business environment where knowledge is central to organizational performance [1]. Organizations trying to embrace KM have many tools, techniques and strategies at their disposal. A vital technique in KM is data mining which enables critical knowledge to be gained from the analysis of large amounts of data and information. The healthcare industry is a very information rich industry. The collecting of data and information permeate most, if not all areas of this industry; however, the healthcare industry has yet to fully embrace KM, let alone the new evolving techniques of data mining. In this paper, we demonstrate the ubiquitous benefits of data mining and KM to healthcare by highlighting their potential to enable and facilitate superior clinical practice and administrative management to ensue. Specifically, we show how data mining can realize the knowledge spiral by effecting the four key transformations identified by Nonaka [2] of turning: (1) existing explicit knowledge to new explicit knowledge, (2) existing explicit knowledge to new tacit knowledge, (3) existing tacit knowledge to new explicit knowledge and (4) existing tacit knowledge to new tacit knowledge. This is done through the establishment of theoretical models that respectively identify the function of the knowledge spiral and the powers of data mining, both exploratory and predictive, in the knowledge discovery process. Our models are then applied to a healthcare data set to demonstrate the potential of this approach as well as the implications of such an approach to the clinical and administrative aspects of healthcare. Further, we demonstrate how these techniques can facilitate hospitals to address the six healthcare quality dimensions identified by the Committee for Quality Healthcare [3].

**Keywords.** Healthcare, knowledge management, data mining,, tacit knowledge, explicit knowledge, knowledge spiral

## 1. Introduction

Healthcare is a growing industry; between 1960-1997 the percentage of Gross Domestic Product (GDP) spent on healthcare by 29 members of the Organizations for Economic Cooperation and Development (OECD) nearly doubled from 3.9-7.6% with the US spending the most (13.6% in 1997). Hence, healthcare expenditure is increasing exponentially and reducing this expenditure, i.e. offering effective and efficient quality healthcare treatment, is becoming a priority globally. Technology and automation have the potential to reduce these costs [3,4]; thus, the adopting and adapting of technologies and new techniques throughout the healthcare industry appears to be the way to stem these escalating costs currently facing the healthcare industry worldwide. We believe the adoption of data mining coupled with Knowledge Management (KM) techniques and strategies is a prudent option for healthcare organizations.

We demonstrate the advantages by firstly highlighting the current challenges facing healthcare and presenting the key quality areas that need to be addressed as underscored by the Committee on the Quality of Healthcare in America. We then describe KM, the major types of knowledge and the knowledge spiral. Next we discuss the role of data and information in healthcare before describing data mining and its role in the knowledge discovery process as well as how it can enable the knowledge spiral to be realized.

Following this, we illustrate the power of data mining by applying the techniques of data mining to a healthcare data set. This serves to highlight the benefits of data mining and KM to healthcare by showing that through realizing the KM spiral with data mining not only is it possible to adhere to the healthcare quality aims stated by the Committee on the Quality of Healthcare in America, but it is also possible to support and enable superior clinical practice and administrative management throughout healthcare. This thereby helps to make data mining and KM strategic imperatives for this industry.

## 2. Challenges Currently Facing Healthcare

Healthcare is noted for using leading edge technologies and embracing new scientific discoveries to enable better cures for diseases and better means to enable early detection of most life threatening diseases. However the healthcare industry globally, and in the US specifically, has been extremely slow to adopt technologies that focus on better practice management and administrative needs [5].

In the final report compiled by the Committee on the Quality of Healthcare in America [3], it was noted that improving patient care is integrally linked to providing high quality healthcare. Furthermore, in order to achieve a high quality of healthcare the committee identified 6 key aims; namely (1) healthcare should be safe – avoiding injuries to patients from the care that is intended to help them, (2) effective - providing services based on scientific knowledge to all who could benefit and refraining from providing services to those who will not benefit (i.e. avoiding underuse and overuse), (3) patient-centered – providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions, (4) timely – reducing waiting and sometimes harmful delays for both those

receiving care and those who give care, (5) efficient - avoiding waste and (6) equitable – providing care that doesn't vary in quality based on personal characteristics.

## 3. Knowledge Management (KM)

KM is a key approach to solve current problems such as competitiveness and the need to innovate which is faced by businesses today. The premise for the need for KM is based on a paradigm shift in the business environment where knowledge is central to organizational performance [1]. This macro-level paradigm shift also has significant implications upon the micro-level processes of assimilation and implementation of KM concepts and techniques [8] i.e., the Knowledge Management Systems (KMS) that are in place. In essence then, KM not only involves the production of information but also the capture of data at the source, the transmission and analysis of this data as well as the communication of information based on or derived from the data to those who can act on it [9].

In today's context of escalating costs in healthcare, managed care, regulations such as the Healthcare Information Portability and Accountability Act (HIPAA) and a technology-savvy patient, the healthcare industry can no longer be complacent regarding embracing technologies and techniques to enable better, more effective and efficient practice management. We believe such an environment is appropriate for the adoption of a KM perspective and key tools and technologies such as data mining.

### *3.1. Types of Knowledge*

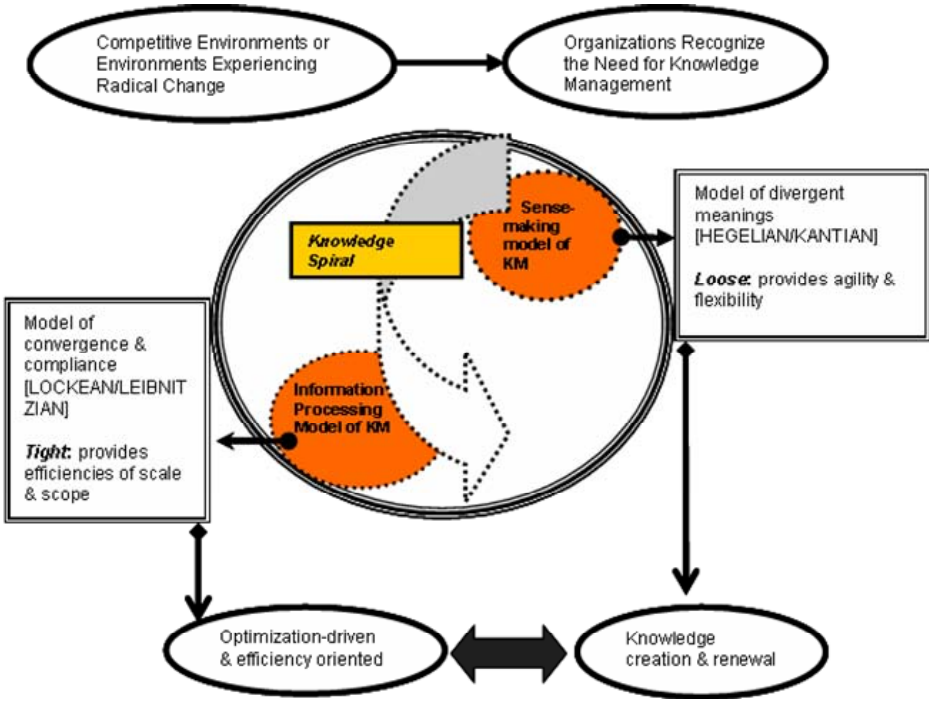
In trying to manage knowledge it is necessary first to understand the binary nature of knowledge; namely its objective and subjective components [5]. Knowledge can exist as an object, in essentially two forms; explicit or factual knowledge and tacit or "know how" [10,11]. It is well established that while both types of knowledge are important, tacit knowledge is more difficult to identify and thus manage [2]. Of equal importance, though perhaps less well defined, knowledge also has a subjective component and can be viewed as an ongoing phenomenon, being shaped by social practices of communities [12]. The objective elements of knowledge can be thought of as primarily having an impact on process while the subjective elements typically impact innovation. Both effective and efficient processes as well as the functions of supporting and fostering innovation are key concerns of KM. Thus, we have an interesting duality in KM that some have called a contradiction [13] and others describe as the *loose-tight* nature of KM [14].

The *loose-tight* nature of KM comes to being because of the need to recognize and draw upon two distinct philosophical perspectives (namely, the Lockean/Leibnitzian stream and the Hegelian/Kantian stream). Models of convergence and compliance representing the *tight* side are grounded in a Lockean/Leibnitzian tradition. These models are essential to provide the information processing aspects of KM, most notably by enabling efficiencies of scale and scope and thus supporting the objective view of KM. In contrast, the *loose* side provides agility and flexibility in the tradition of a Hegelian/Kantian perspective.

Such models recognize the importance of divergence of meaning which is essential to support the "sense-making", subjective view of KM. Figure 1 depicts the Yin-Yang model of KM [5]. This figure shows that given a radical change to an environment or

given a highly competitive environment an organization needs knowledge to survive. From the Yin-Yang depiction of KM, we see that knowledge is required for the organization to be effective and efficient but new knowledge and knowledge renewal (reinforcement and retention of existing knowledge via, a wide variety of methods including active communication, dissemination and short courses) is also necessary. This thereby makes both forms of knowledge important for an organization to capture in order to truly benefit from KM.

Figure 1. Yin-Yang Model of Knowledge Management (adapted from [4])




### *3.2. The Knowledge Spiral*

Knowledge is not static; rather it changes and evolves during the life of an organization. What is more, it is possible to change the form of knowledge; i.e., turn tacit knowledge into explicit and explicit knowledge into tacit or to turn the subjective form of knowledge into the objective form of knowledge [5]. This process of changing the form of knowledge is known as the knowledge spiral [2]. According to Nonaka [2], (1) Tacit to tacit knowledge transfer usually occurs through apprenticeship type relations where the teacher or master passes on the skill to the apprentice, (2) Explicit to explicit knowledge transfer usually occurs via formal learning of facts, (3) Tacit to explicit knowledge transfer usually occurs when there is an articulation of nuances; for example, if a famous surgeon is questioned as to why he does a particular procedure in a certain manner, by his articulation of the steps the tacit knowledge becomes explicit.

and (4) Explicit to tacit knowledge transfer usually occurs as new explicit knowledge is internalized it can then be used to broaden, reframe and extend one's tacit knowledge.

In order to facilitate understanding amongst healthcare professionals, some brief medical examples may serve to illustrate these aspects of the knowledge spiral (see Table 1).

Table 1: Medical examples of the knowledge spiral

| Form of knowledge transfer | Medical Example |
|---|---|
| Explicit to explicit | analogous to initial basic sciences training in medical school |
| Tacit to tacit | analogous to clinical training in the last years of medical school |
| Tacit to explicit | analogous to specialty residency training or subspecialty clinical fellowship training |

Integral to this changing of knowledge through the knowledge spiral is that new knowledge is created [2] and this can bring many benefits to organizations. In the case of transferring tacit knowledge to explicit knowledge for example, an organization is able to capture the expertise of particular individuals; hence, this adds not only to the organizational memory but also enables single loop and double loop organizational learning to take place [15]. Additional benefits of tacit to explicit knowledge transfer include:

- facilitating the emergence of true transdisciplinary medical research and clinical approaches
- enabling the development of novel evaluatice metrics (eg. the *Bonferroni Correction* – a multiple-comparison correction used when several dependent or independent statistical tests are being performed simultaneously)
- the possible emergence of new disciplines or fields (eg. "populomics" – see later discussion)

In healthcare, this may translate, for example, to the developing of better protocols and codes or even further refinement to existing DRGs (Diagnosis Related Groupings).

## 4. Key role of data and information in healthcare

The proliferation of databases in every quadrant of healthcare practice and research is evident in the large number of claims databases, registries, electronic medical record data warehouses, disease surveillance systems, and ad hoc research database systems. Not only does the number of databases grow daily, but even more importantly, so does the amount of data within them. Pattern-identification tasks such as detecting associations between certain risk factors and outcomes, ascertaining trends in healthcare utilization, or discovering new models of disease in populations of individuals rapidly become daunting even to the most experienced healthcare

researcher or manager [16]. Add to all of this the daily volumes of data generated and then accumulated from a healthcare organization administrative system, clearly then, the gap between data collection and data comprehension and analysis becomes even more problematic. IT tools, coupled with new business models such as KM, should be embraced in an attempt to address such healthcare woes [17].

Computerized techniques are essential to helping physicians as well as administrators address this problem. Of particular relevance are the relatively young and growing fields of data mining, knowledge discovery, and KM. Data mining is closely associated with databases and shares some ground with statistics – both strive toward discovering some structure in data. However, while statistical analysis starts with some kind of hypothesis about the data, data mining does not. Furthermore, data mining is much more suited to deal with heterogeneous data fields which are typical of medical databases. Data mining also draws heavily from many other disciplines, most notably machine learning, artificial intelligence, and database technology.

## 5. Data Mining

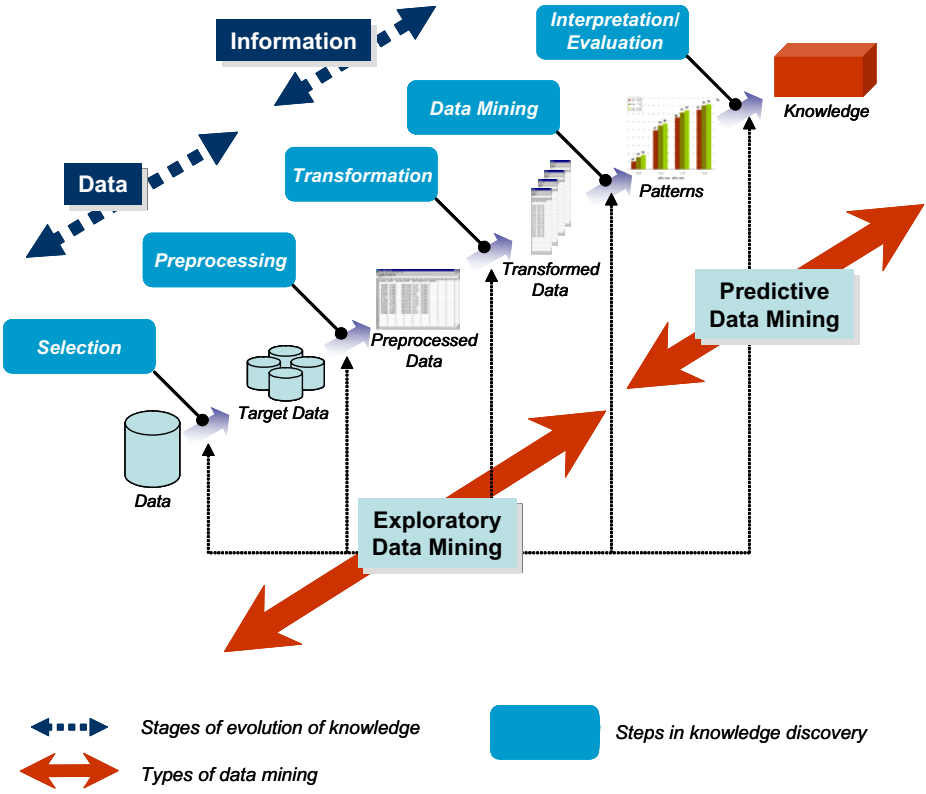
Data mining is the non-trivial process of identifying valid, novel, potentially useful, and ultimately understandable patterns from data [23]. Data mining algorithms are used on databases for model building, or for finding patterns in data. When these patterns are new, useful, and understandable, we say that this is knowledge discovery. How to manage such discovered knowledge and other organizational knowledge is the realm of KM.

When applied to the healthcare context, there has been an increasing prevalence on data mining (and data warehousing) due to the overwhelmingly large amount of clinical data stored in various systems and locations. As shall be discussed later data mining, when combined with effective human-centric and process-based inputs, can provide a powerful conduit to contemporary healthcare organizations and associated decision making. Evidence-based medicine and data can provide further context perhaps leading to innovative clinical interventions; long-term, these could contribute to the reduction and ultimate elimination of inequalities and disparities in health.

Data mining is a step in the broader context of the knowledge discovery process that transforms data into knowledge [23]. Figure 2 shows the knowledge discovery process, the evolution of knowledge from data through information to knowledge [23] and the types of data mining (exploratory and predictive) and their interrelationships. It is essential to emphasize here the importance of the interaction with the medical professionals and administrators who always play a crucial and indispensable role in a knowledge discovery process. This is particularly true when we take into consideration features that are specific to the medical databases. For example, more and more medical procedures employ imaging as a preferred diagnostic tool. Thus, there is a need to develop methods for efficient mining in databases of images, which is inherently more difficult than mining in numerical databases. Other significant features include but are not limited to security and confidentiality concerns and the fact that the physician's interpretation of images, signals, or other clinical data, is written in unstructured English – which is also very difficult to mine [18]. Data issues that data mining helps us wrestle with include: huge volumes of data, dynamic data, incomplete data, imprecise data, noisy data, missing attribute values, redundant data, and inconsistent data. Furthermore, data mining offers a wide variety of models to capture

the characteristics of data and to help knowledge discovery, including, summarization, clustering/segmentation, regression, classification, neural networks, rough sets, association analysis, sequence analysis, prediction, exploratory analysis, and visualization.

Figure 2. Overview of the Knowledge Discovery Process (adapted from [23])




*5.1. Data Mining as an enabler for realizing the Knowledge Spiral*

One of the key strengths of data mining as a tool for facilitating knowledge discovery, and, thereby, its benefit to healthcare, is concerned with its ability to enable the realization of the knowledge spiral. Furthermore, data mining supports both the subjective and objective components of knowledge. In this way, data mining supports the sense making activities as well as the Lokean/Leibnitzian functions and thus the information processing activities. To get a better appreciation of the capabilities of data mining in this context, let us consider each of the types of knowledge transfer described in section 3.2 (and depicted in Table 2 below). Key to the power of data mining is that with the one technology we have the potential to address all four aspects of the knowledge spiral; and hence supporting all possible transferring of knowledge on both

the clinical practice and administrative sides of healthcare. The implications for this technology are tremendous especially when we factor in the high level of data and information intensiveness in the healthcare environment.

Table 2. Data Mining as an enabler of the Knowledge Spiral

| *TO* / *FROM* | **EXPLICIT**[1] | **TACIT** |
|---|---|---|
| **EXPLICIT** | Performing exploratory data mining, such as summarization and visualization, it is possible to upgrade, expand, and/or revise current facts and protocols. | By assimilating and internalizing knowledge discovered through data mining, physicians can turn this explicit knowledge into tacit knowledge which they can apply to treating new patients |
| **TACIT** | Interpretation of findings from data mining helps the revealing of tacit knowledge, which can then be articulated and stored as explicit cases in the case repository. | Interpreting treatment patterns for example for hip disease discovered through data mining enables interaction among physicians – hence making it possible to stimulate and grow their own tacit knowledge. |

We illustrate specifically how data mining enables the realization of the knowledge spiral in healthcare with the following example.

Table 3: Drugs Administered To Patients

| Patient ID | Drug |
|---|---|
| 1 | D1, D2 |
| 2 | S3, D4, D5 |
| 3 | D3, D1, D2 |
| 4 | D3, D5, D1 |
| 5 | D5, D2 |

The above table (Table 3) is an example of explicit knowledge stored in a medication repository. Using data mining, the following patterns can be discovered:

- D1 is administered to 60% of the patients (i.e., 3/5)
- D1 and D2 are administered together to 40% of the patients (i.e., 2/5)
- D2 is administered to 67% of the patients who are given drug D1 (i.e., 2/3)

As the physicians try to understand these findings, one physician could explain that D2 has to be given with D1 for patients who had a heart attack at age 40 or less. Thus the following rule can be added to the rule repository: If a patient's age is <= 40 years and the patient had a heart attack and D1 is administered to the patient, then D2 should also be administered to that patient. This is an example of existing tacit knowledge,

[1] Each entry explains how data mining enables the knowledge transfer from the type of knowledge in the cell row to the type of knowledge in the cell column.

since it originated from the physician's head transferring to new explicit knowledge that is now recorded for everyone to use.

As physicians discuss the implications of these findings, tacit knowledge from some physicians gets transferred into tacit knowledge for other physicians. Thus, during the interaction of physicians from different specialties an environment of existing tacit to new tacit knowledge transfer occurs which consequently realizes the sense-making component of the Yin Yang model in Figure 1. We summarize such knowledge transfers in Table 4.

Table 4: Data Mining As An Enabler Of The Knowledge Spiral In Healthcare

<table>
<tr><th>FROM \ TO</th><th>EXPLICIT[2]</th><th>TACIT</th></tr>
<tr><td>EXPLICIT<br><table><tr><th>Patient ID</th><th>Drug</th></tr><tr><td>1</td><td>D1, D2</td></tr><tr><td>2</td><td>S3, D4, D5</td></tr><tr><td>3</td><td>D3, D1, D2</td></tr><tr><td>4</td><td>D3, D5, D1</td></tr><tr><td>5</td><td>D5, D2</td></tr></table></td><td>• D1 is administered to 60% of the patients<br>• D1 and D2 are administered together to 40% of the patients<br>• D2 is administered to 67% of the patients who are given drug D1</td><td>  </td></tr>
<tr><td>TACIT<br>  </td><td>If a patient's age is <= 40 years and the patient had a heart attack and D1 is administered to the patient, then D2 should also be administered to that patient.<br>Interaction</td><td>  </td></tr>
</table>

[2] Each entry gives an example of how data mining enables the knowledge transfer from the knowledge type in the cell row to the knowledge type of the cell column.

## 6. Benefits of Knowledge Management and Data Mining to Healthcare

Data mining can be applied at the clinical as well as the hospital administration levels. At the clinical level, for example, data mining could help in early detection of diseases from historical databases of symptoms and diagnosis – thus providing an early warning system that leads to a much more effective healthcare system. At the hospital administration level, for example, data mining could help in tracking certain kinds of anomalies or frauds, which may reveal areas of potential improvement and may help realignment of resources (e.g., equipment, personnel, etc.). Other benefits of data mining include expanding individual as well as organizational knowledge, and therefore enabling the healthcare system to do more with its given resources – i.e., achieve more efficiencies. This is especially useful in addressing situations of shortages of resources such as the shortage of nurses (a key problem currently in the US) by being able to do more with the limited nursing staff the organization has. The possibilities of using data mining in healthcare are virtually limitless. The strategic significance of data mining and KM technologies to healthcare is hardly disputable in our opinion. Thus, we believe competitive and forward-looking healthcare organizations need to initiate pilot applications and proof of concept projects to start reaping the benefits of these technologies.

Data mining is now increasingly being used in a variety of healthcare database environments, including insurance claims, electronic medical records, epidemiologic surveillance, and drug utilization. Companies are also using data mining to help improve patient services. For example, United Healthcare, a $10.5 billion health-care services company in Minneapolis, USA with an IT budget of about $320 million and an IS staff of 2500, is using data-mining applications to learn more about treatment and preventative care for patients [19]. Data mining will enable clinicians and managers to find valuable new patterns in their databases, leading to potential improvement of resource utilization and patient health. As these patterns are based on clinical or administrative practice, they represent the ultimate in evidence-based medicine and healthcare. In particular, healthcare data can be analyzed for trends and/or changes, and the appropriate healthcare professionals are alerted should major shifts in trends or changes are discovered.

We summarize the role that KM and data mining play in achieving the aims of healthcare as stated by the Committee on the Quality of Healthcare in America [3], identified earlier in section 2, in Table 5 below. This serves to highlight the ubiquitous benefits of data mining to all areas of quality healthcare treatment and hence, demonstrating how data mining adds significant value to healthcare delivery.

Table 5: Data Mining and knowledge management supporting the Key Quality Aims

| Aim | KM/DM Potential Sample Applications |
|---|---|
| Safety | Auto-alerting when drugs of inappropriate reactions are prescribed together |
| Effectiveness | Age and weight appropriate dose recommendation |
| Patient-Centered | Enabling patients' self-service capabilities in appointment scheduling and secure personal information access |
| Timeliness | Prediction of disease occurrence and hence timely and proactive treatment |
| Efficiency | Accounting and billing analytics to identify and correct inefficiencies |
| Equity | Automatic auditing and control capabilities |

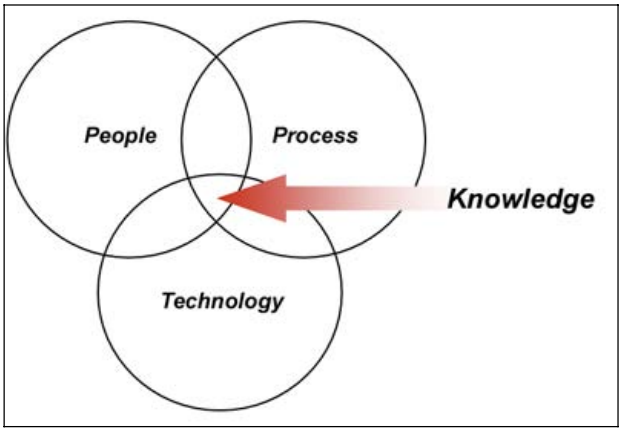
## 7. Application of KM to different healthcare contexts

KM is a still relatively new phenomenon and a somewhat nebulous topic that needs to be explored. However, organisations in all industries, both large and small, are racing to integrate this new management tool into their infrastructure. KM caters to the critical issues of organisational adaptation, survival, and competence in the face of increasingly discontinuous environmental change [20]. Essentially, it embodies organisational processes that seek synergistic combination of data and information processing capacity of information technologies, and the creative and innovative capacity of human beings.

### *7.1. Generic knowledge management*

Knowledge is a critical resource in any organisation and is also crucial in the provision of healthcare. Specifically, organisational knowledge (not just in healthcare scenarios) exists at the confluence of people, process and technology (Figure 3).

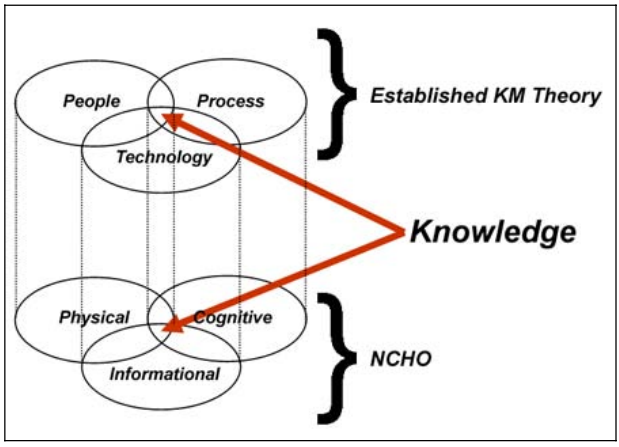
Figure 3. Essential schematic of KM †



### *7.2. Network-Centric Healthcare Operations (NCHO)*

KM can also provide the solution to the current and prospective challenges for clinical and healthcare contexts as it provides the tools, techniques and strategies to facilitate the necessary paradigm shift for making our healthcare system truly functional in the 21st century. To illustrate this, if we map (Figure 4) the essential schematic of KM and the essential schematic of NCHO, we see that the key unifying component or common denominator is knowledge. Thus, KM is the key for establishing and most importantly sustaining NCHO.

Figure 4. Link between KM theory and NCHO †




### *7.3. Knowledge for Urban Health contexts*

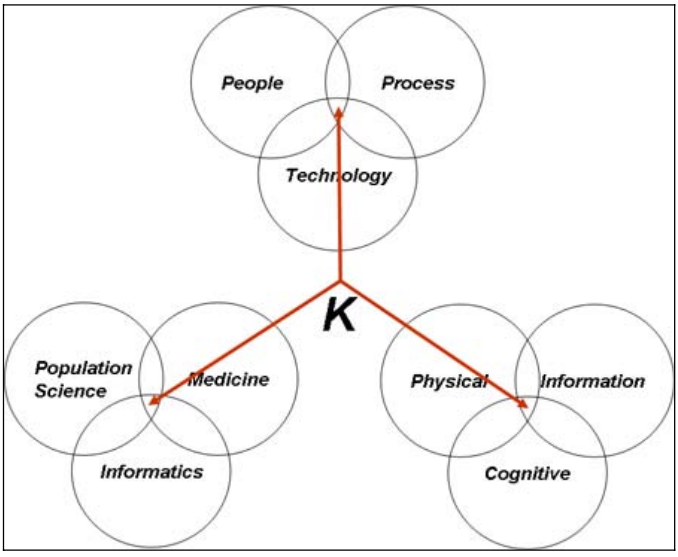
Recent advances in the computer sciences and information technology fields have spawned several methodological advances in the biological and molecular sciences (eg, DNA chip technology and microarray analysis), enabled quantum leaps in molecular and submolecular medicine, and catalyzed the emergence of whole new fields of study such as proteomics, phenomics, nutrigenomics, and pharmacogenetics. Perhaps, in like manner, with the emergence of eHealth, the behavioral and population sciences may be on the verge of a similar information technology–based scientific revolution. New eHealth solutions may soon permit the real-time integrative utilization of vast amounts of behavioral-, biological-, and community-level information in ways not previously possible. Behavioral algorithms and decision support tools for scientists could facilitate the analysis and interpretation of population level data to enable the development of "community (population) arrays" or community-wide risk profiles, which in turn could form the foundation of a new "populomics." [21].

This confluence of three seemingly disparate concepts (population science, medicine and informatics) has parallels with the growing field of KM as well as the NHCO figure discussed above; the connection can be seen clearly in Figure 5. It has been argued that such improvements and improvements in disciplines as supposedly diverse as organizational behavior, ICT, teamwork, artificial intelligence, leadership,

training, motivation and strategy have been equally applicable and relevant in the clinical and healthcare sectors as they have been in others. Clinicians and managers have used many of these disciplines (in combination) many times before; they may have, inadvertently and partially, carried out knowledge management *avant la lettre* [24].

Understanding and disentangling the myriad determinants of disease, particularly within the context of urban health or health disparities (inequalities in health), requires a transdisciplinary approach. Transdisciplinary approaches draw on concepts from multiple scientific disciplines to develop integrated perspectives from which to conduct scientific investigation and provide needed care. Attempts to organize and understand complex bio-socio-behavioral systems have led some researchers to *Chaos Theory* and *Complexity Theory* as constructs to facilitate the understanding about health and its relationship to diverse processes and outcomes [27-30]. In reality though, it is likely that these approaches are beyond the practical usefulness of many clinicians and scientists. Recently, elaboration of the Sociobiologic Integrative Model (SBIM) [31] has been advanced as a theoretic contruct to facilitate the integration of knowledge from many different fields. Utilizing the SBIM along with the principles of KM may offer health disparities researchers and clinicians providing care in the urban environment significant promise towards the quest to improve Urban Health and eliminate health disparities/inequalities.

Figure 5. KM as a unifier (K=Knowledge) †




## 8. Discussion

KM is a still relatively new phenomenon and a somewhat nebulous topic that needs to be explored. However, organisations in all industries, both large and small, are racing

to integrate this new management tool into their infrastructure. Essentially, it embodies organisational processes that seek synergistic combination of data and information processing capacity of information technologies, and the creative and innovative capacity of human beings.

Any successful knowledge discovery effort should start with a thorough understanding of the problem as well as the data. Exploratory data mining enhances such understanding and possibly enables participants to formulate some hypotheses. The next phase in the discovery process involves a development of some model - classification, clustering, or prediction. The model needs to be evaluated – data-tested and professionally-verified. Where to start in the knowledge discovery process is a matter of where an organization is positioned along a knowledge discovery continuum. At the early stages, one usually starts with a pilot project of a limited scope which serves as a proof of concept for the feasibility and utility of the data mining technology within the given organizational context. Such a pilot requires an organizational championship and a significant amount of data, as the knowledge discovery process is data-driven and data-intensive by nature. The outcome of the pilot should provide sufficient metrics for evaluating the usefulness of the data mining technology.

The efficacy of data mining needs to be balanced with organizational requirements. For any healthcare organization to succeed, it needs to excel in a number of key processes (ie. patient diagnosis, care treatment, etc.) that are necessary for it to achieve its mission. If the processes are repetitive, automation is possible via the use of IT [24] and, therein, data mining techniques.

Medical knowledge stems from scores of multiple sources. The design principles for the management of knowledge sharing and its global impact are a complex mix of issues characterized by varying cultural, legal, regulatory, and sociological determinants [25].

Because such knowledge has been created by humans, as a result of interpreting information (eg. critically appraising journal articles and making sense of health sites on the internet), there is a level of subjectivity which can create uncertainty; there is an inherent risk of misinterpretation when the user does not possess skills for making sound judgements about the extent to which this knowledge applies to his or her problem situation [26].

The major value of data mining is to enable healthcare stakeholders to realize the potential of the knowledge spiral. This would generally aid in the elucidation of new medical knowledge not just in the quest to improve the quality of medical care, but also specifically in the generation of new clinical interventions as well as the reduction and ultimate elimination of inequalities in health and health disparities.

## 9. Conclusions

Our paper has served to identify the key role for data mining and KM in healthcare. We did this by discussing some of the major challenges facing healthcare today. Next, we discussed KM and in particular highlighted the role of the knowledge spiral. Our discussion of data mining served to demonstrate how data mining enables the realization of the knowledge spiral. The power of data mining lies in the fact that it can realize the transferring of knowledge in the knowledge spiral in the Yin Yang model of KM we presented.

Data mining and KM then can be seen to afford many advantages to enabling cost effective, high quality healthcare to ensue as we discuss in this paper; but of even greater appeal is that these techniques are relevant to both the clinical practice and administrative management concerns of healthcare, thereby making them a most powerful and apropos remedy to the numerous maladies and challenges currently facing healthcare. Therefore, we believe data mining and KM are critical necessities for any forward thinking healthcare organization.

## 10. Acknowledgements

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## References

[1] P. Drucker, *Post-Capitalist Society,* Harper Collins: New York, 1993.
[2] I. Nonaka, "A dynamic theory of organizational knowledge creation", *Organizational Science*, 5, 14-37, 1994.
[3] Committee on Quality of Healthcare in America Institute of Medicine, Crossing the Quality Chasm-a New Health System for the 21st Century, National Academy Press, Washington, DC, 2001.
[4] N. Wickramasinghe, "IS/IT as a Tool to Achieve Goal Alignment: a theoretical framework", *International Journal of Healthcare Technology Management,* 2,(1/2/3/4), 163-180, 2000.
[5] N. Wickramasinghe and G. Mills, "MARS: The Electronic Medical Record System The Core of the Kaiser Galaxy", *International Journal of Healthcare Technology Management*, 3(5/6), 406-423, 2000.
[6] R. Stegwee and T. Spil, *Strategies for Healthcare Information Systems*, Idea Group Publishing: Hershey. 2001.
[7] N. Wickramasinghe and JB. Silvers, "IS/IT The Prescription To Enable Medical Group Practices Attain Their Goals", *Healthcare Management Science*, 2001
[8] J. Swan, H. Scarbrough and J. Preston, *Knowledge Management – The Next Fad To Forget People?*, Proc 7th European Conference in Information Systems, 1999.
[9] T. Davenport, and L. Prusak, *Working Knowledge*, Harvard Business School Press, Boston, 1998.
[10] M. Polyani, *Personal knowledge: towards a post-critical philosophy*, University Press Chicago:Chicago, 1958.
[11] M. Polyani, *The Tacit Dimension*, Routledge and Kegan Paul:London, 1966.
[12] R. Boland and R. Tenkasi, "Perspective making perspective taking", *Organizational Science*, 6, 350-372, 1995.
[13] U. Schultz, "Investigating the contradictions in knowledge management" Presentation at IFIP Dec, 1998.
[14] Y. Malhotra, "Knowledge management and new organizational form" in Malhotra (Ed.), *Knowledge Management and Virtual Organizations*, Idea Group Publishing:Hershey, 2000.
[15] G. Huber, "The Nature and Design of Postindustrial Organizations", *Management Science*, 30(8), Aug, 928-951, 1984.
[16] J. Holmes, P. Abbott, P. Cullen, L. Moody, K. Phillips and B. Zupan, "Clinical Data Mining: Who does it, and what do they do?"; *AMIA 2002 Symposium*, Nov 9-13, 2002.
[17] S. Berinato, "CIOs at the Heart of Health-Care Change"; *CIO Magazine*, Jun 15, 2002.
[18] M.K. McGee, "High-Tech Healing"; *Information Week*, September 22, 1997.
[19] K.J. Cios (Ed.), *Medical data mining and knowledge discovery*, Physica-Verlag, 2001.
[20] Rubenstein, A. and Geisler, E. (2003) Installing and Managing Workable Knowledge Management Systems, Praeger Publishers, Westport, CT.
[21] Gibbons MC (2005) A Historical Overview of Health Disparities and the Potential of eHealth Solutions, J Med Internet Res 2005;7(5):e50, <URL: http://www.jmir.org/2005/5/e50/>
[22] Bali RK (2005), *Clinical Knowledge Management: Opportunities and Challenges*, IGP:USA, 2005, pp.xii

[23] Fayyad, P-S and Smyth, U., "From Data Mining to Knowledge Discovery: An Overview", in *Fayyad, Piatetsky-Shapiro, Smyth, Uthurusamy, Advances in Knowledge Discovery and Data Mining, AAAI Press / The MIT Press, Menlo Park, CA*, 1996.
[24] R.K. Bali, A.N. Dwivedi and R.N.G. Naguib, "Issues in Clinical Knowledge Management: Revisiting Healthcare Management", In Bali (Ed.) *Clinical Knowledge Management: Opportunities and Challenges*, IGP:USA, 2005.
[25] S. Laxminarayan, "Foreword", In Bali (Ed.) *Clinical Knowledge Management: Opportunities and Challenges*, IGP:USA, 2005.
[26] R.K. Bali, D.D. Feng, F. Burstein and A.N. Dwivedi, "Introduction to the special issue on advances in clinical and health-care knowledge management", *IEEE Trans Inf Technol Biomed,* Jun;9(2):157-61, 2005.
[27] A. Garfinkel, M.L. Spano, W.L. Ditto, J.N. Weiss, "Controlling cardiac chaos", *Science*, 257(5074):1230-1235, 1992.
[28] J.N. Weiss, A. Garfinkel, M.L. Spano, W.L. Ditto, "Chaos and chaos control in biology", *J Clin Invest*, 93(4):1355-1360, 1994.
[29] L.F. Olsen, W.M. Schaffer, "Chaos versus noisy periodicity: alternative hypotheses for childhood epidemics", *Science*, 249(4968):499-504, 1990.
[30] C.W. Tidd, L.F. Olsen, W.M. Schaffer, "The case for chaos in childhood epidemics. II. Predicting historical epidemics from mathematical models", *Proc Biol Sci*, 254(1341):257-273, 1993.
[31] M.C. Gibbons, M. Brock, A.J. Alberg, T. Glass, T.A. LaVeist, S.B. Baylin et al., "The Socio-biologic integrative model: Enhancing the integration of socio-behavioral, environmental and bio-molecular knowledge in urban health and disparities research", *Journal of Urban Health*, 84(2):198-211, 2007.

# Platforms

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*IOS Press, 2008*



# Improving Healthcare Services using Web Based Platform for Management of Medical Case Studies

Cristina OGESCU[a], Claudiu PLAISANU[a], Florian UDRESCU[a], Silviu DUMITRU[b]
[a]*The Company for Research, Development, Engineering and Manufacturing for Control Systems – IPA S.A, Bucharest, Romania*
[b]*Institute for Computers – ITC SA, Bucharest, Romania*

**Abstract.** The paper presents a web based platform for management of medical cases, support for healthcare specialists in taking the best clinical decision. Research has been oriented mostly on multimedia data management, classification algorithms for querying, retrieving and processing different medical data types (text and images). The medical case studies can be accessed by healthcare specialists and by students as anonymous case studies providing trust and confidentiality in Internet virtual environment. The MIDAS platform develops an intelligent framework to manage sets of medical data (text, static or dynamic images), in order to optimize the diagnosis and the decision process, which will reduce the medical errors and will increase the quality of medical act. MIDAS is an integrated project working on medical information retrieval from heterogeneous, distributed medical multimedia database.

**Keywords.** Medical case, web based platform, second medical opinion

## Introduction

The Internet has become the effective information exchange strategy in healthcare services. One of the most important aspects of this strategy is the possibility offered to healthcare professionals to exchange information, to discuss, to take or to give advice to other professionals, by creating a web based large medical information database. A well organized medical database can compensate human memory limitations and provides a specialized environment for improving patient care, research and education. The MIDAS platform develops a user-friendly platform for searching, mining and processing medical information available in a multimedia medical database. The platform is a very helpful tool for professional training inside medical virtual communities and will assure the support for communication between healthcare professionals from medical communities to analyze difficult medical cases and to establish the intervention methods or the adequate medical care.

## 1. General Description

The MIDAS platform is implemented as a web portal application, supporting:

- Management of medical information organized in clinical case studies;
- Exchange of information between healthcare specialists

The information platform is used to maintain a dialogue with the system in order to optimize medical diagnosis. Thus, users can interact with the system in order to publish a specific case which requires attention or to ask for extra information to optimize medical diagnosis, as well as to participate at discussions on different medical topics. The platform enables the dialogue and the consultation between healthcare professionals by creating descriptive models for medical data, information and image acquisition, as well as displaying them in an intelligent and user friendly graphical interfaces [1].

IT experts monitor and manage the execution environment of the platform.

The main modules of the MIDAS platform are:

- Management of heterogeneous medical information module;
- Consultation module between healthcare professionals;
- Monitoring module visible only for the administrator of the portal.

Also, the platform provides e-mail services for collaboration between specialists and a forum for healthcare professionals to exchange medical, training, support information.

### *1.1. Functional Requirements*

Starting from an abstract level, we have identified two major functional requirements for the most important modules of the platform (management of medical heterogeneous data module and specialists consulting module). These requirements are:

- *Publishing a clinical case* – MIDAS will enable the publishing of a medical case by the usage of predefined templates. An interesting clinical case can be published in order to inform the specialists that works in the same medical area (in this context, the medical case will contain imaging investigations, patient data, medical analysis, diagnosis and treatment possibilities). Also the clinical case can be published in order to obtain additional information from other specialists in the same field (the clinical case will contain imaging investigations, patient data, medical analysis and the requirements for diagnosis and treatment).
- *Assisting difficult case studies* – A registered user has the possibility to view all cases which need assistance to give a personal opinion to help the owner of the case to take the best decision for diagnosis and treatment.

At a more detailed level, the two main requirements presented above can be extended in this manner:

- *Logging in and authentication* of *users (health specialists)* – the platform will enable the logging in and the authentication of users (doctors) that will publish clinical cases.
- *Clinical case elaboration* – after authentication, the user will elaborate the clinical case that he will publish.
- *Publishing a clinical case* – there will be two possibilities for publishing a clinical case: to inform the medical personnel from that area (in this context, the medical case will contain imaging investigations, patient data, medical analysis, diagnosis and treatment possibilities) or to ask for supplementary information from other medical specialists (the clinical case would contain

imaging investigations, patient data, medical analysis and the requirements for diagnosis and treatment).

- *Medical case assistance* - A registered user can post a personal opinion to help the owner of the case in taking the best decision for diagnosis and treatment.
- *Monitoring and administrating a clinical case* – after publishing a clinical case, the user that created it has the possibility to monitor the evolution of the case.

## 2. Portal Presentation

The portal is organized in four main sections:

- Personal Account;
- Shared medical case studies
- Medical case assistance
- General information.

### *2.1. Personal account*

Only registered users, healthcare specialists have access in this section. The user can update his profile, can register new cases for sharing medical data or for asking a second opinion to solve the case, or can view a list of favourite cases selected from the portal database.

In the system, a medical case is structured using the patient health record model from the Romanian hospitals. The main sections are:

- Personal data: name, surname, personal identification number, age, sex. To ensure the anonymization of the case, only sex and age will be public for other users. The identification data are available only for the user who registers the case in the system.
- Anamnesis
- Anatomical Systems Investigations. The section contains a description of all accomplished medical investigations.
- Laboratory: contains information about patients' laboratory investigations.
- Image Section. In this section the clinician can upload significant medical images to describe the case (radiography, echography, endoscopy, MRN, CT). The images could be static (JPG, PNG, GIF, DICOM format) or dynamic (AVI or DICOM format) [2], [3]. We present a screenshot of this section in figure 1:


Figure 1

### *2.2. Shared medical case studies*

In this section there are listed all public clinical cases. The access is unlimited including unregistered users (students, healthcare authorities, etc). The user can create a filter based on available parameters (e.g. diagnosis, medical speciality, period) to extract information from the database. Only the registered users can create a favourite case list selecting medical cases which will be viewed in the "Personal Account" section.

### *2.3. Medical case assistance*

This section is structured like a forum and is visible only for the registered users. The cases can be viewed using a list of criteria based on user requests. For every case saved in the database requiring assistance, a registered user can view all stored information about the case and give an opinion to help the owner of the case to establish the diagnosis or/and the appropriate treatment. The users can create a favorite case list selecting medical cases which will be viewed in the "Personal Account" section

A screenshot of this section is presented in Figure 2.

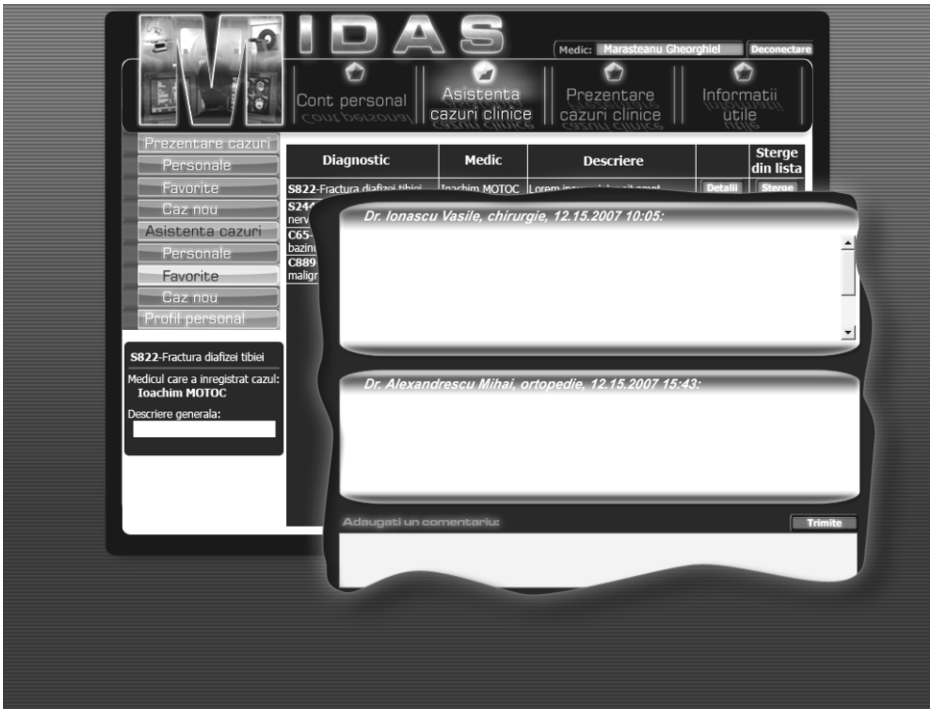


Figure 2

### *2.4. General information*

This section presents public information about registered users, medical events, research news and is managed by the administrator of the portal.

## 3. Technical description of the MIDAS platform

The MIDAS platform is a WEB portal that is able to perform various operations: recording and retrieving of medical case studies, communication between healthcare specialists in order to solve medical cases.

The hardware architecture of the platform consists in:

- database server [4]
- web application server.

The platform is developed using open-source technologies (MySQL database and PHP for web application development) in order to reduce the costs of the implementation and the administration of the portal.

The operating system installed on the central server is Windows 2003 Server R2i, including IIS 6.0 web server.

The sitemap of the portal is shown in Figure 3:

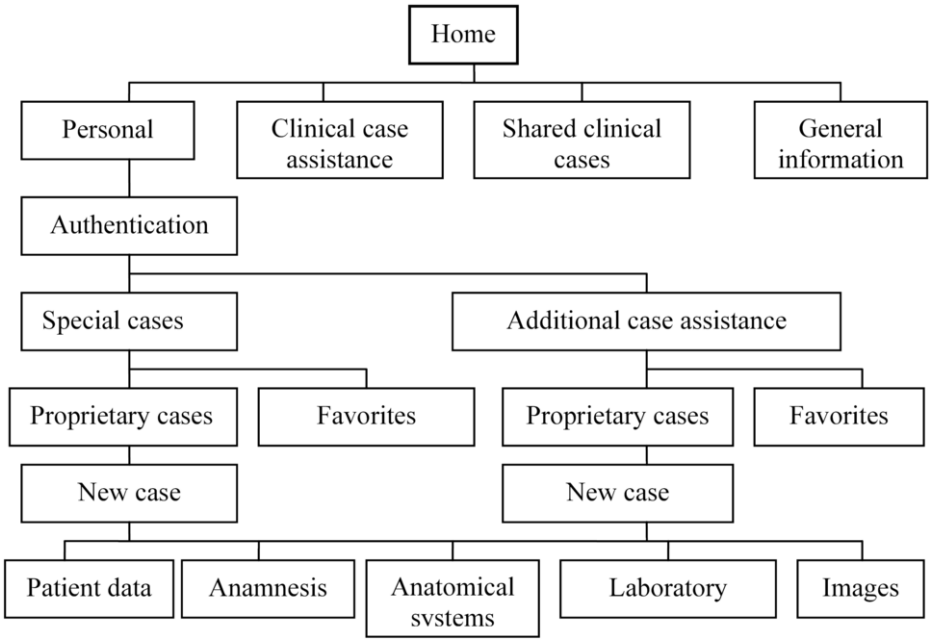


Figure 3

## 4. Privacy and confidentiality

MIDAS platform ensures privacy and confidentiality of medical information over the internet using a set of rules which refers to:

- Extracting identification information from the medical case studies and using an encryption algorithm to save data in the database. Only the owner of the case has access to this information.
- All identification information is extracted from the DICOM files when they are uploaded and saved in the database.
- Only the cases that are registered as public are visible for all the persons who access the web portal
- For registration in the portal the user must contact the administrator and transmit required data in order to be verified if he is a valid healthcare specialist.

All data stored in the database is protected by the requirement to specify a valid username and password in order to update or delete the data.

## 5. Conclusion

This article has presented the MIDAS platform designed for the management of heterogeneous medical data that integrates medical and information concepts, support

for healthcare professionals in taking the best clinical decision for prevention, diagnosis and treatment.

The project main benefits are the following:

- Reduction of the medical errors;
- Processing of large objects such multimedia medical data;
- More efficiency by supporting remote reading and diagnosis of clinical cases;
- Continuous training of healthcare professionals;
- Access of specialists to relevant medical information;
- Support for education and research in medical sciences;

The project will be an information support for healthcare specialists, a useful tool which aims to achieve the goals referred by evidence-based medicine concept.

## References

[1] Anca Daniela Ionita. Modelarea UML in ingineria sistemelor de programe. ALL 2003
[2] Manolis Wallace, Ilias Maglogiannis, Kostas Karpouzis, John Enderle. Image and Signal Processing for Networked eHealth Applications
[3] medical.nema.org
[4] www.mysql.com

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# Design and Development of a Knowledge driven Web based ECG Data monitoring and Diagnostic Tool in Lab-view

H.R.SINGH and Manju SINGH
*Biomedical Measurements and Standards Group*
*National Physical Laboratory New Delhi110012, India*
*hrst_52@rediffmail.com & manjus.10@gmail.com*

**Abstract:** Knowledge driven technological developments, the growth and speed of application oriented products in the field of web based services, medical technology and information science, the use of sensor networks for remote patient monitoring is currently playing a major role in quality healthcare delivery to the masses. However, further research need to be done for more effective diagnosis and treatment of diseases remotely. An improved web based, knowledge driven, patient data monitoring and diagnosis system remotely, is developed to acquire, store and process the data using specially developed GUI (Graphical User Interface) on lab-view platform. The GUI displays, communicates and processes vital biomedical parameters such as Heart rate (HR), beat to beat ratio (R-R), QRS and QT intervals etc after acquiring ECG, pulse rate, body temperature etc. from the patient's body sensors. The system detects any emergency condition automatically, if the patient develops any abnormality in his heart rate or irregularity in rhythm heart line and establishes direct connectivity between specialists and patient. The provision to store the online data on remote PC in auto mode is given. The storage of data files on demand on local and remote PC and online data communication between the two is done through shared variables. A case study to evaluate the performance and to verify the experimental implementation is conducted on two patients with varying heart rate (HR) and varying rhythm and the results were found exactly to be in accordance with the expected outcome.

**Keywords:** Embedded Intelligence, Patient Monitoring, Telemedicine, Assisted Living, Sensor Networking, Bio-telemetry, Electrocardiogram (ECG).

## 1. Introduction

The overwhelming impact and incredible speed of technological developments, the use of smart sensors [1] [2] and embodiment of intelligence [3] into the systems have made it possible to provide a safe, secure and reliable care services to the masses, particularly in remote areas through bio-telemetry [4]. It has been noticed, that in far remote areas, the poor or almost no availability of modern medical facilities to treat the common old age ailments such as cardio vascular failure, diabetes and blood pressure related problems have lead to several deaths, which could have been otherwise averted. On the contrary, a majority of urban populations in metro cities have been found struggling to fight the menace of stressful life arising out of dramatic changes in lifestyle and degradation of social boundaries. The unbearable caring cost in private nursing homes,

the cost and burden of shifting a critical state patient from one hospital to another for specialized treatment or from remote place to nearby medical center and also the unnecessary expenditure on the living and maintenance of a companion care personnel have led to the development of a new innovative idea of providing better care services to the elderly people at their homes. Smart devices and intelligent technologies will take care of the patients or elderly people enjoying a self-determined life in a more preferred environment of their own homes and beds without any fear of external invasion of privacy.

Indeed, the society is on the gateway of a new age and technology is poised to give a new sense of freedom [5] [6] by integrating the developments in computer networking, Internet services and medical technology. The transmission of biomedical parameters, most commonly ECG data transmission on mobile phones [7] under critical conditions has been quiet common during the past few years, but with certain limitations of no real time transmission and limited storage space due to memory restrictions. The system automation connecting the patient to the specialist remotely, on detecting an emergency condition plays a vital role in providing immediate diagnosis and a quick and timely medication. The idea of acquiring vital biomedical signals through sensors on the body, signal conditioning and processing these signals before being transferred to the specialists at a distance in real time, to obtain medical expert advice instantly, finds wider applications in assisted living [8] [9] to an ever increasing population of elderly people.

This paper describes a versatile, cost effective and application oriented web based analytical, informative and corrective action taking tool employing systems and devices like Internet, PC's and specially developed Graphical User Interfaces (GUI's). Sensor data acquisition with amplification, filtering and subsequently transmitting it using short range FM transmitter which is picked up by FM receiver, before it is processed by the central processing station (Local PC) using Lab-View platform [10] is described. A specially developed algorithm for automatic alert stage detection, which connects the patient to the doctor for instant decision, is incorporated. A case study on two patients with varying heart rate and rhythm to evaluate the performance and implementation strategy was conducted and results found to be in accordance with the expected outcome.

## 2. Methodology

### *2.1. Data Acquisition and Processing*

Data such as body temperature, pulse rate, ECG etc. from different sensors and electrodes put around the patient's body are acquired for further amplification and proper signal conditioning before fed to a short range (8-10 meters) FM transmitter operating at 108MHz for onward transmission to a nearby central processing station (Local PC), where it is picked up by an FM receiver tuned to the same base frequency. These signals are further acquired into NI Lab-view data acquisition card (PCI-6281). Data acquisition card is a high-speed multi function card with 16 analog inputs at 18 bits and on board low pass filter for rejection of high frequency noise and preventing aliasing. Upon receiving at Local PC the signals are processed to find out vital parameters such as QRS intervals, QT intervals and beat to beat (RR intervals) etc. These parameters/ waveforms are displayed on local PC as well as on remote PC for

monitoring the patient condition online. Apart from these parameters calculated from ECG waveforms, the beats per minute (bpm) of the patients are also monitored simultaneously through an electret microphone for better correlation with the calculated bpm. A block diagram of the complete system is shown in Fig 1.

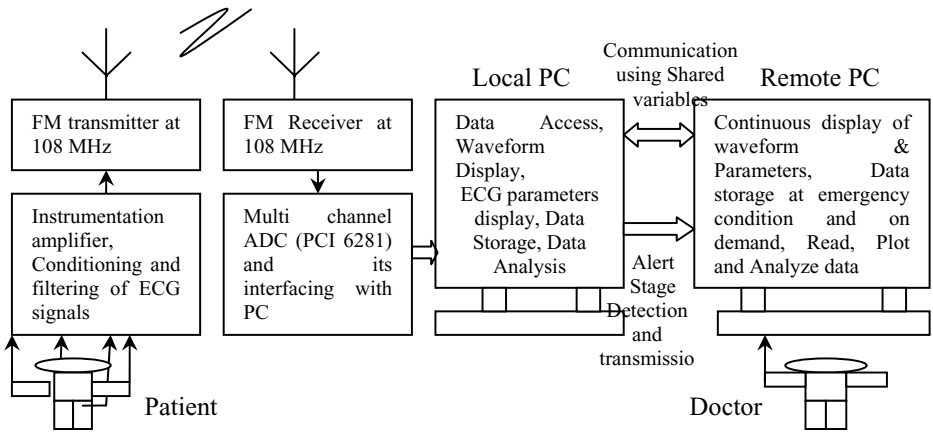



**Figure 1:** Block diagram of Lab-view based Tale-monitoring system

The automatic emergency condition detection is a new concept in the system's automation [11], where the software detects an alert stage by calculating from the body signals, a number of parameters and comparing them with the set limits under normal conditions. Normally, the heart rate is calculated using peak detector and then calculating R-R intervals as follows.

HR=60/R-R interval (bpm), RR interval is calculated by measuring time interval between two consecutive peaks.

QRS and QT intervals are calculated on the basis of slope and threshold value of ECG waveforms. A peak detector is used after ECG signal is filtered using Butterworth filter (0.8 to 18Hz) to obtain information about QRS peaks. The signal slope, zero crossing and threshold values are used to determine QRS and QT intervals. A window of 500ms after R position is used to determine S & T wave. The T wave peak is assumed to occur at the zero crossing and a window of 200 ms before R position is used to determine Q wave. If the difference between two consecutive heart beat is found more than 100 bpm or less than 50 bpm, an alert condition is sounded on the remote PC for the attention of the doctor. Provision for calculating several other important parameters like QS and QT interval etc. have also been incorporated in auto mode as well as direct display of these parameters on remote PC for the convenience of the doctor to arrive at quick diagnostic conclusion. The system displays the ECG waveform and parameters such as Heart Rate, QRS and QT interval etc in auto mode and connects the patient to the specialists on finding any crossover in the set values of calculated bpm or any irregular rhythm of the patients automatically as explained in the flow chart Fig.2.

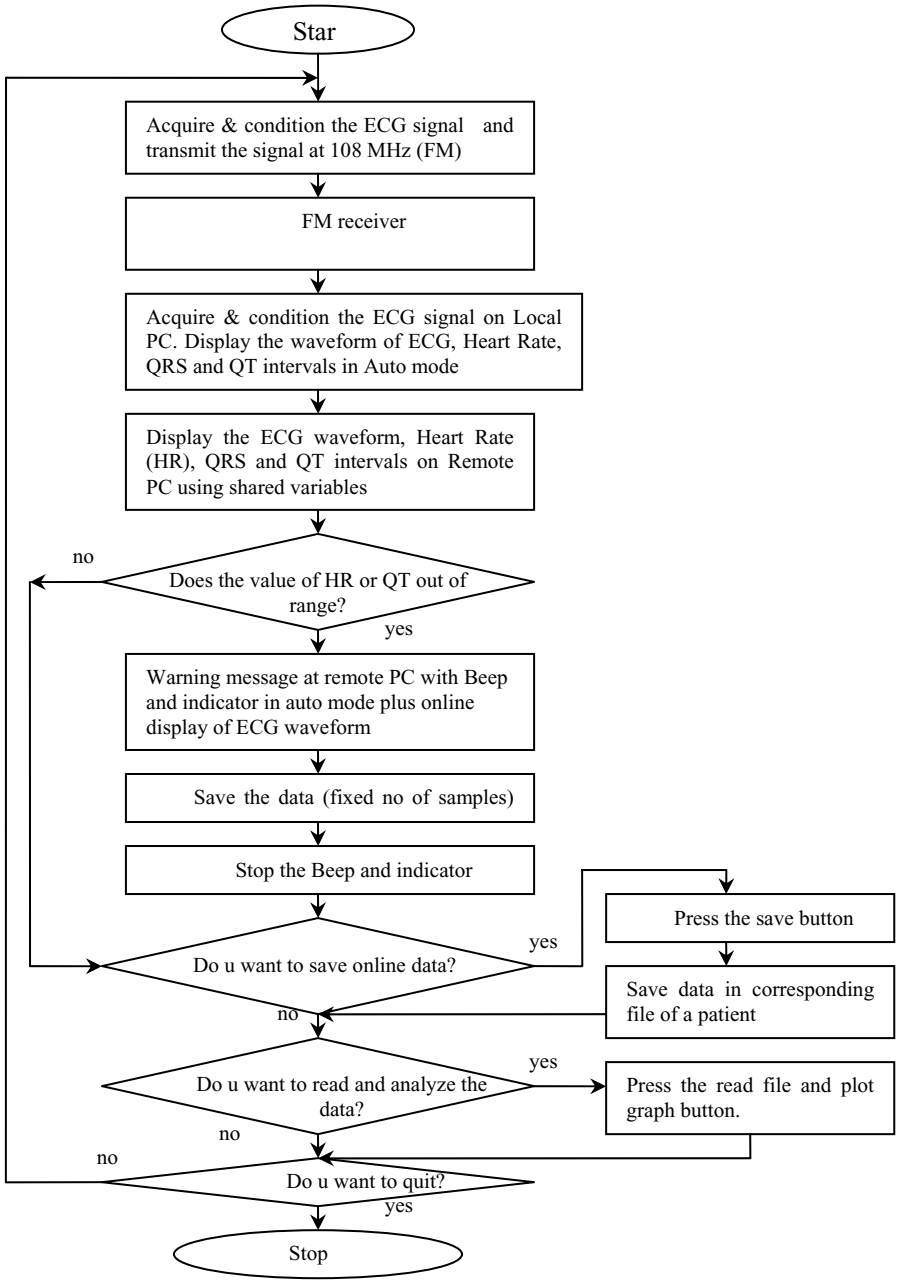



**Figure 2:** Flow chart for Alert stage detection and delivery

LABVIEW programs are called virtual instruments or VIs, which contain three components the front panel, the block diagram and the icon and connector pane. The front panel includes controls and indicators. The block diagram includes wires, front

panel icons, functions, possibly sub VIs and other Lab-view objects. A VI within other VI is called a sub VI. One of the block diagrams implementing the flow chart as shown in Fig. 2 for calculation of initial parameters and their transmission to remote PC in Lab view environment is shown in Fig.3.

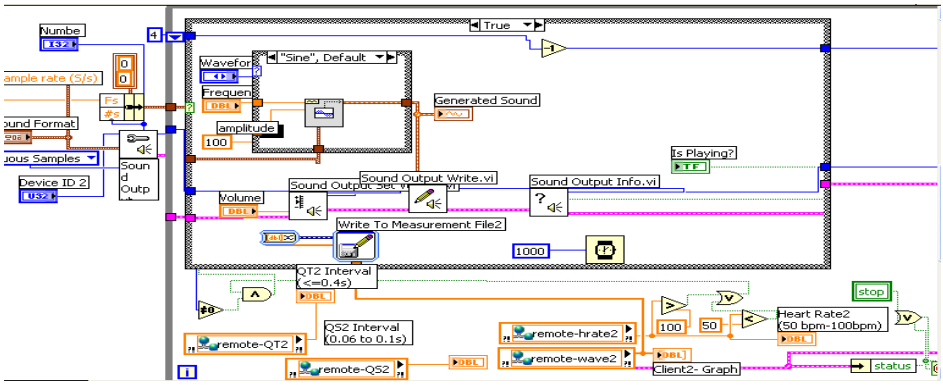
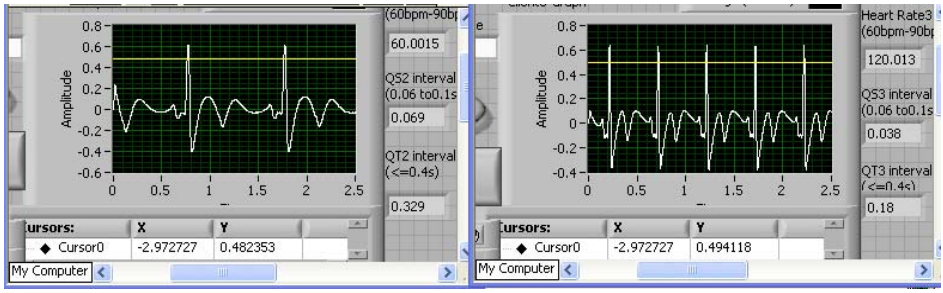
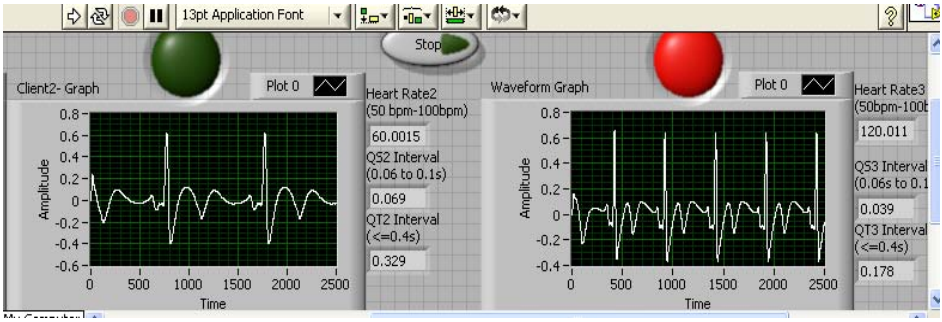



**Figure 3:** Block diagram for display and calculating ECG waveform and its parameters

A multifunctional graphical user interface performing a number of tasks such as data acquisition, analysis, send data, receive data, report generation with sounding beep and red indicator on remote PC is shown in Fig.4




(a) (b)




(c)

**Figure 4:** Front Panel for display of ECG & parameters of Patient1 (a), Patient2 (b) on Local PC and Multiple Patients (c) on Remote PC.

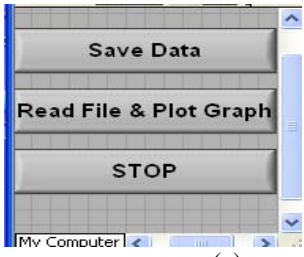
The above figure displays online ECG data acquisition of two patients simultaneously on local PC (Top) and remote PC (bottom) as well as save the data in auto mode on remote PC on developing any emergency threat. However, number of patients is not restricted and depends upon the data acquisition card capacity, which is sixteen in present case.

### *2.2. Data Analysis*

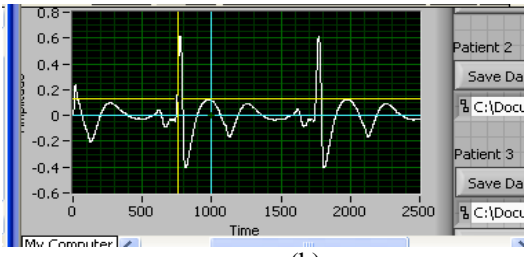
Data analysis can be performed by the specialist at both the ends for quick and efficient diagnosis of the ailment. The specialist or the caregiver at the patient side can analyze the data manually by placing the cursor at the appropriate positions to calculate the required parameters such as heart rate, PR, QRS and QT intervals, as explained in system's flow chart and displayed in Fig. 5. The software constructed around a client server model also calculates these parameters automatically, which is designed in such a way, that it connects the patient to the doctor and generates an alarm signal on remote PC immediately on detecting any alert stage. Online data flow using shared variables takes place to the remote PC through local PC. Shared variables are configured software items that can send live data between local and remote PC. The shared variables engine uses the NI lab-view data transfer protocol to write and allow users to read live data.

### *2.3. Read file, Plot graph and Auto save*

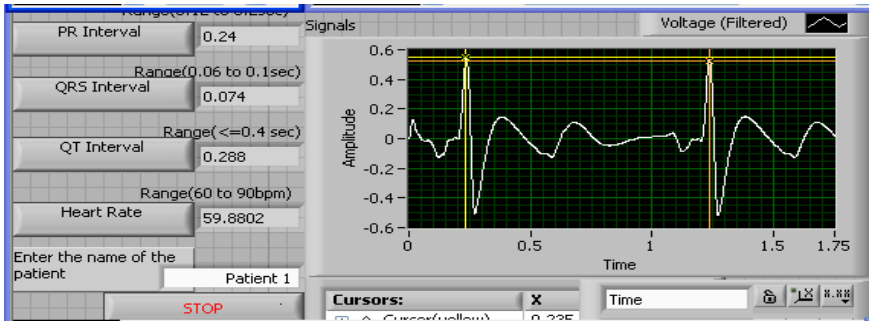
The system is capable of recording live data for a limited period in auto mode, until the doctor attends the patient on remote PC, helping the doctor to see the previous recording for analysis purposes. The data can be saved on demand on both PC's by pressing "**save data**" button on the main VI as shown in Fig. 5(a). The data files saved on demand are shown in Fig. 5(b). These files can be read and plotted back to further analysis by pressing read file & plot graph button on the panel as shown in Fig. 5(c).




(a)




(b)



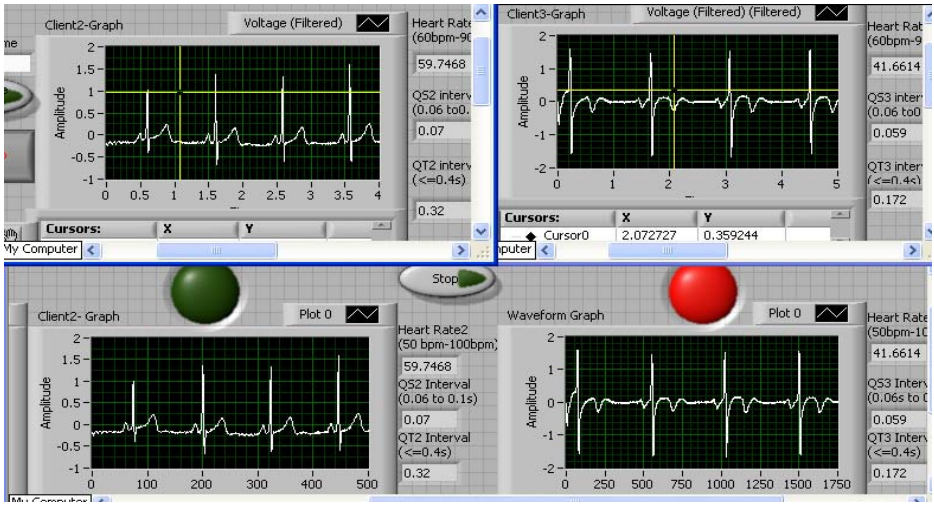

(c)

**Figure (5):** Main VI (a) Sub VI to save data on demand (b) Sub VI to Read File, Plot graph and Analysis of parameters (c).

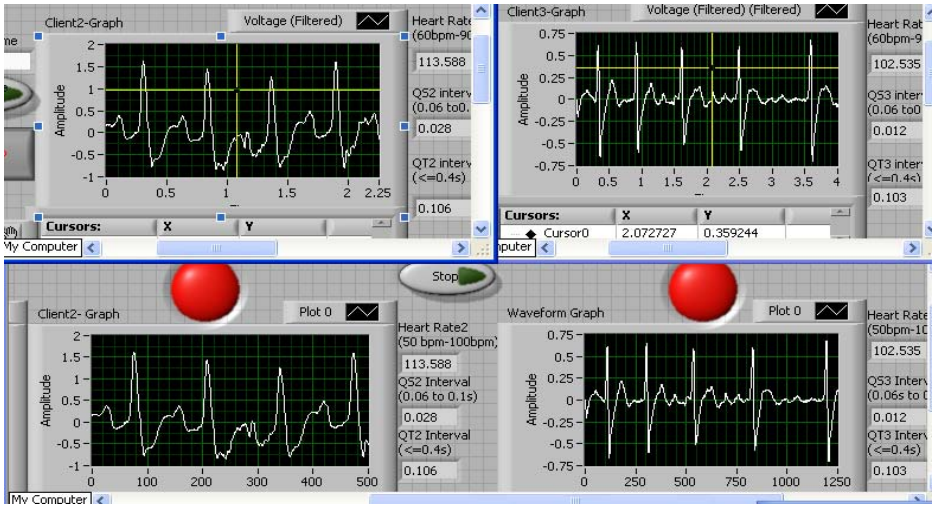
A comprehensive patient report can be generated by using data logging option and can be retrieved in future to know the patient history.

## 3. Performance Evaluation: A Case Study

An Arrhythmia is a heartbeat that is too fast, too slow or irregular (uneven) and is caused by problems with heart's electrical system. The term bradycardia describes a heart-rate that is too slow (less than 50 beats per minute). Tachycardia usually refers to a heart rate that's too fast (more than 100 beats per minute). Figure 6 shows the results obtained after a case study [12] was conducted on two different patients with normal heart rate, abnormal heart rate (50>HR>100) and irregular rhythm. It is found that as long as the heart rate is normal, it is being displayed on both the PC's simultaneously with no red signal or sounding beep, but the instance, HR drops below 50, indicator on remote PC glow red with sounding beep Figure 6(a). A similar case study for HR greater than 100 and irregular rhythm is displayed in figure 6(b).




(a)




(b)

**Figure 6:** ECG data of patients with normal and below normal heart rate on local (top) and remote (bottom) PC (a), ECG data of patients with above normal heart rate and irregular rhythm on local (top) and remote (bottom) PC (b).

## 4. Conclusion and Future work

A versatile and dependable real time web based patient ECG data monitoring and diagnostic tool using Lab-view platform has been implemented. Specially developed GUI's and systems software store the data in data files on local PC and simultaneously extracts out a number of biomedical parameters from the captured ECG signals to match with the set boundary limits and rhythm of the patient heart line data. Crossing over to either side or finding an abnormal rhythm the software connects the patient to the doctor on remote PC for an on spot diagnosis of the disease. The ECG data is saved in auto mode at remote PC, if the doctor is not currently available at the site. The approach is based on shared variables to transfer, communicate and save live data between local and remote PC using a specially developed GUI's in auto mode as well as recalling data on demand. The case study performed to evaluate the performance and implementation strategy finds the system to be a perfect on the spot analytical tool in remote monitoring, diagnosing and caring to the high-risk cardiac patient. The data compression to save storage space and the data security during data transfer over the network, need further investigation, keeping in view the nature and importance of such applications.

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## References

[1] Yang B.H., Rhee S. and Asada H.H. (1998) " A twenty four Hour Tele-Nursing System using a Ring sensor', Proc. Of Int. Conf. On Robotics and Automation Leuven, Belgium., pp. 16-20
[2] Malan D., Fulford-Jones T., Welsh M. and Moulton S.(2004) ' CodeBlue: An Adhoc Sensor Network Infrastructure for Emergency Medical Care', Proc. Inl Workshop on Wearable and Implant able Body Sensors Networks, London, UK, pp.55-58
[3] Baran A. and Kilagiz Y. (2006) 'A Biotelemetry System with Microcontroller and Integerated Web Server in Wireless IEEE 802.11B TCP/IP Network', Erciyes Universitesi Fen Bilimeri Enstitusu Dergisi, Vol 22, No1-2, pp. 1-10
[4] Lin J.C. (1999) ' Applying telecommunication technology to health care delivery- the current status and challenges of tele-medicine', IEEE Engineering in Medicine and Biology, Vol. 18, No.4, pp.28-31
[5] "Popularizing Scientific Knowledge, Promoting Social Development: http://english .people.com.cn
[6] Forkner-Dunn J. (2003) 'Internet based Patient Self-care: The Next Generation of Health Care Delivery', J Med Internet Res., Vol.5, No. 2:e8
[7] Daja N., Reljin B.(2001) ' Telemonitoring in Cardology- ECG Transmission by Mobile Phone', Annals of the Academy of Studenica, Vol.4, pp.63-66
[8] Alwan M., Dalal S., Mack D.' Kell S.W., Turner B., Leachtenauer J. and Felder R. (2006) 'Impact of Monitoring Technology in Assisted Living: Outcome Pilot', IEEE Trans on Info Tech in Biomed, Vol. 10, No.1,192-198
[9] Virone G., Alwan M., Dalal S., Kell S., Turner B., Stankovic J.A. and Felder R. 'Behavioral Patterns of Older Adults in Assisted Living', Paper Identification Number : TITB_00087_2006
[10] Labview User Manual, National Instruments, Part number 320999E-01, 2003.
[11] T.D. Chowdhary B. S., Memon M. S. (2004) "The Potential of Telemedicine System: An Approach Towards a Mobile Doctor', National Conference on Emerging Technologies, pp.106-111
[12] Goldberger AL, Amaral LAN, Glass L, Hausdorff JM, Ivanov PCh, Mark RG, Mietus JE, Moody GB, Peng CK, Stanley HE. PhysioBank, PhysioToolkit, and PhysioNet:Components of a New Research Resource for Complex Physiologic Signals. *Circulation* 101(23):e215-e220

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*IOS Press, 2008*



# Improving Healthcare Middleware Standards with Semantic methods and technologies

Isabel Román[a,b], Jorge Calvillo[b,a], Laura M. Roa[a,b] and Germán Madinabeitia[a]
[a] *University of Seville*
[b] *CIBER-BBN*
*Escuela Superior de Ingenieros, Camino de los Descubrimientos S/N, 41092 Sevilla, Spain*
*isabel@trajano.us.es*

**Abstract.** A critical issue in healthcare informatics is to facilitate the integration and interoperability of applications. This goal can be achieved through an open architecture based on a middleware independent from specific applications; useful for working with existing systems, as well as for the integration of new systems. Several standard organizations are making efforts toward this target. This work is based on the EN 12967-1,2,3, developed by CEN, that follows the ODP (Open Distributed Processing) methodology, providing a specification of distributed systems based on the definition of five viewpoints. However, only the three upper viewpoints are used to produce EN 12967, the two lower viewpoints should be considered in the implementation context. We are using Semantic Grid for lower views and Semantic Web and Web Services for the definition of the upper views. We analyze benefits of using these methods and technologies and expose methodology for the development of this semantic healthcare middleware observing European Standards.

**Keywords:** Interoperability, Semantic Grid, Semantic Web Services, Healthcare Middleware.

## 1. Introduction

One of the most obvious benefits of integration in the healthcare domain is the possibility of compilation, visualization and management of the distributed clinical information related to a patient, this can ease the healthcare professional tasks and improve the quality of service. But the integration of applications and the reutilization on software resources inside a healthcare organization can bring many other benefits related to different issues as, for example, assistance, management or research. Under the present circumstances of proliferation of applications, mutually isolated and incompatible, that are already available in the market, installed, and operational in healthcare organizations, effectively supporting specific needs of users, a critical issue is to make possible the integration and interoperability of them, thereby securing investments already made and allowing continuity of the service whilst facilitating a gradual migration of existing proprietary, monolithic systems towards the new concepts

of openness and modularity. The cost-effectiveness of the solutions, especially when projected on the scale of the whole organization, represents another crucial aspect to be evaluated carefully [1]. This critical issue explains why several research groups and standard organizations are making efforts to solve integration and interoperability problems [2-5] within healthcare systems.

Integration and interoperability are easier to achieve if different applications and components are developed following distributed objects paradigm and inside an open architecture based on a middleware independent from specific applications and capable of integrating knowledge and business logic and of making them available to diverse, multi-vendor applications. The architecture should be intended as a basis both for working with existing systems, allowing specific models to be integrated, as well as for the planning and construction of new systems.

Knowledge and business logic common to different sectors of the healthcare organization shall therefore be integrated in a specific architectural layer of the underlying information system and shall be accessible through services based on public and stable interfaces. The ultimate objective of such a structure is to build an open federation of complementary heterogeneous systems, spread over the territory, individually autonomous but also capable of interworking to effectively meet different needs in the healthcare environment as care, social, research or administrative, increasing the overall effectiveness of the activities carried out.

## 2. Material and method

### *2.1. Distributed components architecture in the healthcare domain*

As we have exposed in previous works [6] integration and interoperability solutions are often based on the decomposition of tasks inside the healthcare organization and the design of a specialized components-based architecture [1,5]. Components can be aggregated to a higher level of composition in order to offer services that are more complex.

Standardization is a cornerstone for integration. Standards already exist and will continue being defined for supporting specific requirements, both in terms of in situ user operations and with respect to communication procedures. Some healthcare middleware approaches are developed by standardization organizations, like CEN [1,7-8] or OMG [5].

The purpose of the three-part European standard EN 12967-1,2,3 [1,7-8] for a healthcare service architecture, is to identify a set of information services used within healthcare information systems, supporting specific requirements of the target organization, as well as being capable of co-operating and interworking according to the requirements of the organization as a whole. This allows describing the architecture of any generic healthcare information system as a federation of heterogeneous applications, interacting and co-operating through a set of components and information services.

An important basis for the production of this service architecture standard, is the methodology of ODP [9-11] (Open Distributed Processing). The objective of ODP standardization is the development of standards that allow the benefits of distributing information processing services to be realized in an environment of heterogeneous IT

resources and multiple organizational domains. ODP provides a five layered approach to the definition of information services. However, only the three upper levels, Enterprise viewpoint, Information viewpoint and Computational viewpoint are used to produce this standard. The two lower views should be considered in a specific implementation context, they are not defined in the standard but in our work we have made same decisions, justified forward.

**The enterprise viewpoint** shall provide a guideline for the definition of the requirements for information exchange within a healthcare enterprise, with a focus on the purpose, scope and policies of the system.

**The information viewpoint** is concerned with the kinds of information handled by the system and constraints on the use and interpretation of that information. It provides a methodology for detailing the semantics of the information to be processed as an information model and considering those provided by other standards for health informatics. This viewpoint supports the solution of semantics conflicts in the integration of systems.

**The computational viewpoint** shall give guidance on the distribution through functional decomposition of the system objects that interact at defined interfaces. This is the basis for the solution of functional integration of systems inside the healthcare organization.

**The engineering viewpoint** on the system and its environment focuses on the mechanisms and functions required to support distributed interactions between objects in the system.

**The technology viewpoint** describes the implementation of the ODP system in terms of a configuration of technology objects representing the hardware and software components of the implementation. It is constrained by cost and availability of technology objects (hardware and software products) that would satisfy this specification.

Any architectural solution inside the European context should be compliant with EN12967-1, 2, 3 and, consequently, with ODP methodology.

### *2.2. Semantic technologies improving distributed processing*

Nevertheless these architectures are domain specific and mainly based on the rigid description of information models and interfaces identified as fundamental in the healthcare environment. This paradigm makes difficult the integration of systems not compliant with these standards, needing the development of complex specific interceptors, or the inclusion of new facilities not considered when the standard middleware was described.

Some general architectures for distributed computing are focusing in the development of universal middlewares where any new service or application could be easily integrated. These are based on semantic techniques for the description of component's behavior and the management of domain ontologies.

Integration models for components or agents, supported by semantic management, are based on a formal and machine-computable description of the behavior, requirements and interaction mode of the system agents. At the same time it is necessary to use a common ontology between components to represent the managed domain concepts and the methods to make the mappings between the federated and the local ontologies.

Once the target of an agent is specified, the use of a semantic description of the other system components eases the automatic search, selection and invocation of interfaces for the target resolution.

This integration method is very "open" in the sense that it is not necessary a normalized knowledge of the offered services and of the interaction procedures with the deliverer agent to make use of its facilities. This knowledge could be learnt in the moment when the agent needs it and through the formal interfaces definition. This way, the scalability of the solution is ensured.

The development of middlewares based on this integration paradigm, supported by semantic management, is a high priority and a relevant research line at this moment. Semantic Web [12-14] and Semantic Grid [15,16] technologies are examples of those with more number of research groups involved.

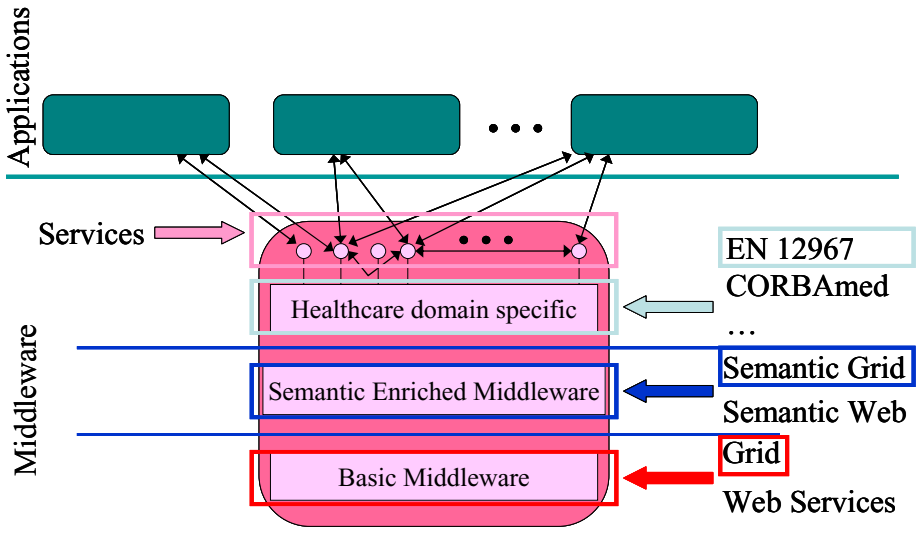


Figure 1. Using semantic middleware in healthcare domain

The use of these technologies as the underlying middleware for health and medical systems, as figure 1 shows, could be crucial in the accomplishment of a global infrastructure that facilitates health knowledge management wherever and whenever it were needed. This implies that the use of these semantic technologies for the specification of the two lower viewpoints (engineering and technology) in the traditional distributed processed model introduced in ODP standard could improve the integration facilities of the healthcare middleware making lighter the specification of the upper levels.

## 3. Results

### *3.1. Applying methods and technologies to clinical guidelines components*

Although the methods that we propose are developed thinking in the integration of all the components regarding the whole healthcare organization, and even though the chosen technologies are not healthcare domain specific, we are applying our research to clinical guidelines management components. As we have exposed in previous works [17] we are following European standard EN 12967 [1,7-8], making contributions to the higher viewpoints.

In order to represent the ontology needed by these components we have reviewed several languages for representing clinical guidelines [18,19], considering, among other issues, the merging with EN 12967 information viewpoint and the ability to cover as more concepts as possible, EON [20-24] has been selected as our starting point. The EON architecture is an evolving suite of models and software components designed to build guideline-based applications. In this framework, the guideline model includes:

- a patient data model: which defines the structure of patient information used by the EON system;
- a medical concept model: that primarily defines the medical vocabulary used for encoding guidelines; and
- the EON guideline model, called Dharma: which defines the structure of a computable EON guideline.

Dharma is viewed as the core of a set of models, each one focused on a particular issue of the guideline modelling, such as temporal abstractions or criteria definition. This model is object-oriented and consists of classes that describe guideline entities as a sequence of structured temporal steps. Dharma is non-monolithic, meaning that the guideline model can be extended with additional classes that capture new guideline behaviour. This feature makes it suitable for our purposes.

We do not rule out to make extensions if some aspects, not covered with EON, have to be considered; of course we will follow EON extension mechanism when this is needed. In particular we are improving it with time management, using the main Asbru [25] time concepts.

### *3.2. Choosing the technology: Enhancing services with semantic grid*

As it was mentioned above, the two lower views, the engineering and the technology viewpoints, should be considered only in a specific implementation context. In this paper, according to the goal of interoperability between distributed and heterogeneous system, it is proposed a semantic grid computing implementation for improving the healthcare middleware.

Among the most extended middlewares for integration we could refer to CORBA, Web Services and Grid. We have chosen Grid because the interaction mechanisms between objects are more extensive than in the others, and therefore it is closer to ODP philosophy where interactions are not exclusively in the client/server paradigm.

The semantic grid middleware comprises mechanisms and functions required to support distributed interactions between objects in the system, so it is related to the engineering viewpoint of the distributed architecture, and allows the application of

semantically enhanced services. In this context, the reference architecture S-OGSA [26] (Semantic-OGSA) will be used, proposed as part of the EU-IST project Ontogrid [27], which is based on the existing OGSA [28] (Open Grid Service Architecture).

OGSA, published by the Global Grid Forum, aims to enable interoperability between services independent of implementation, location, or platform. To do this, it defines standard mechanisms for creating, naming, and discovering persistent and transient Grid service instances; provides location transparency and multiple protocol bindings for service instances; and supports integration with underlying native platform facilities. The OGSA approach supports the necessary mechanisms for the grid computing and it will be the base middleware.

On the other hand, S-OGSA extends OGSA to support the explicit handling of semantics, and defines the associated knowledge services to support a spectrum of service capabilities. A definition of the semantic resources that are supplied and consumed amongst the services extends the general model of the grid. With S-OGSA there are new entities in the model of the grid (a Grid Entity is anything that carries an identity on the grid, including resources and services); Knowledge Entities, that represent or could operate with some form of knowledge as ontologies, rules or knowledge bases; Semantic Bindings, that come into existence to represent the association of a Grid Entity with one or more Knowledge Entities; and Semantic Grid Entities, that are either the subject of a semantic binding, are themselves a semantic binding, or a Knowledge Entity.

Regarding to the technology viewpoint, as the semantic grid is a recent initiative, its implementation is far to be a reality. At the moment, only an OGSA implementation can be realized. To do this, there are many products and toolkits that enable different aspects of grid computing. One of the most well known toolkits is the Globus Toolkit, which provides components and services conforming to existing and evolving standards that can be used as the basis for a grid computing solution.

Among the common components that can be chosen from within the Globus Toolkit there are security systems as firewalls, networking elements, systems management tools to help determine availability and performance within the grid, and all the components related to the storage.

Furthermore, an S-OGSA implementation is being developed in the context of the OntoGrid project. This implementation, called OntoKit, will introduce the provision of semantics to the grid. In OntoKit additional services that are able to deal with semantics (ontologies, annotation, and metadata) and can be used by any semantic grid application are implemented. Actually, OntoKit forms another conceptual layer between the application specific services and the grid middleware. That middleware is Globus Toolkit 4, and OntoKit extends it like S-OGSA does with OGSA.

Considering the semantic provisioning services, the following components are obtained:

- The ontology service: will allow access to the information contained in ontologies, including their concepts and relationships.
- The reasoning service: is in charge of inferring new information and checking constraints, by taking into account the knowledge stored in ontologies.
- The semantic binding service: will provide storage and access mechanisms for Semantic Bindings.
- The annotation service: will aim to structure unstructured data according to a predefined model, such as a domain ontology, and it will attach descriptive

information to a service in order to facilitate processing involving the capabilities of the service.
- Coordination and negotiation services: which allow resources with competing goals to reach agreement, as well as giving support to intelligent decision-making, coalition and team formation and dynamic task allocation.
- Intelligent debugging tool: which provides functionalities related to the monitoring semantic grid applications.

### *3.3. Some possible advantages for clinical guidelines management*

Using the technologies presented above we can expect several advantages. In this section we discuss some improvement that their introduction could achieve, for the particular case of the clinical guidelines management. We are developing several GRID components that do a simple management of clinical guidelines, as the storing, recovery, query…

We use guidelines expressed in XML, using EON and HISA concepts; these are clearly exposed in the architecture common ontology, described in the information viewpoint. This gives us the possibility of link the knowledge in these guidelines with the knowledge implicit in other elements of the organization such as the patient electronic healthcare record (EHR), or in other biomedical components inside the architecture, because they understand the same "languages".

The interfaces to these components are described in the computational viewpoint and the interchanged data are conforming to the information viewpoint, the architecture ontology. Any necessary new functionality that has to be introduced in the architecture must use the same information viewpoint so it is going to be understood by the rest of components.

Regarding to the engineering and technological viewpoints we are using the grid and Semantic grid principles and technologies. This implies that information and computational viewpoints must be formalized in the appropriate S-OGSA languages. The knowledge services of S-OGSA will be available in our architecture; it will give us the advantage of design more complex services reusing the basic services for clinical guidelines management, always following the same philosophy. Some possible complex knowledge management services could be:

- Services for the automatic selection of the appropriate clinical guidelines, for a particular patient care.
- Services for the physician decision support in the elaboration of the care plan for a particular patient, linking his/her EHR knowledge and the clinical guidelines recommendations. When several guidelines could be applied (especially in comorbidity patients), these services could discover contradictions between them; helping the physician in his care decisions.
- Services for the evaluation of the correct execution of a clinical guideline; considering the patients EHR.
- Services for the support in the elaboration of new clinical guidelines. This could be achieved using the implicit knowledge about patients already registered in the organization EHR system (tests, diagnosis, treatment, evolution…).

Several interesting examples using grid and semantic grid technologies for providing different services have been recently published in a special issue of the IEEE

publication “Transaction on Information Technology in Biomedicine” [29]. This is a sign of the relevance of these new technologies. Although these examples are very different from our research, the integration of these heterogeneous applications clearly can improve the healthcare knowledge management and it is facilitated thanks to the use of these middleware semantic technologies.

## 4. Conclusions

We are developing the five ODP viewpoints for Clinical Guideline Management Components. Our advances in the three upper viewpoints (enterprise, information and computational) are closer to the European Standard, in the sense that we have to extend it with concepts related to clinical guideline management not included in the standard. This could feedback the standard, improving it. It is essential to consider that the healthcare domain is such extensive that it is difficult to develop a standard covering all the implied issues. The specification of these viewpoints, centered in the guideline management services, considered the use of specific semantic technologies and services when it is necessary.

Our work in the lower viewpoints (engineering and technology) explores the benefits of using the Grid, enhanced with semantic, in the deployment of healthcare middleware. We have exposed some possible advantages of these new technologies applied to components for clinical guidelines management.

This approach pursues the integration of heterogeneous healthcare components and applications not only thinking about the interoperability and reuse of software, but also the optimum management of the healthcare organization knowledge. This knowledge could be related to assistance, research, management, education, or any other activity of interest in the organization. The paradigm that we are following for the integration supports a better knowledge management, exploiting synergy among different knowledge domains inside the organization.

## Acknowledgments

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## References

[1] CEN /TC 251.Secretariat: SIS, "EN 12967-1:2007. Health informatics - Service architecture - Part 1: Enterprise viewpoint," 2007.
[2] CEN /TC 251 Published standards. Last visited March. 2008. URL: http://www.cen.eu/CENORM/Sectors/TechnicalCommitteesWorkshops/CENTechnicalCommittees/Standards.asp?param=6232&title=CEN%2FTC+251
[3] HL7 web site. Last visited March. 2008. URL: www.hl7.org
[4] B. B.Wein, M. Eichelberg, A. Ihls, and E. Poiseau, "IHE Integrating the Healthcare Enterprise-an update for Information Technology Infrastructure for 2005," International Congress Series 1281, pp. 169-174, 2005.
[5] CORBAmed: OMG, "Healthcare Domain Task Force standards" Last visited March 2008. URL: http://healthcare.omg.org/Roadmap/corbamed_roadmap.htm

[6] I. Román, L.M. Roa, G. Madinabeitia and L.J. Reina. "A Standard Ontology for the Semantic Integration of Components in Healthcare Organizations". Medical and Care Compunetics 3. In: Book.: IOS Pres, 2006. Editor: L.Bos et al. ISBN: 1-58603-620-3, ISSN: 0926-9630. pp 257-265
[7] CEN /TC 251.Secretariat: SIS, "EN 12967-2:2007. Health informatics - Service architecture - Part 2: Information viewpoint," 2007.
[8] CEN /TC 251.Secretariat: SIS, " EN 12967-3:2007 Health informatics - Service architecture - Part 3: Computational viewpoint," 2007.
[9] ITU-T, "Rec. X901-Information technology – Open distributed processing – Reference Model: Overview," 1997.
[10] ITU-T, "Rec. X.902-Information Technology-Open distributed processing-Reference model:foundations," 1995.
[11] ITU-T, "Rec. X903-Information technology – Open distributed processing – Reference Model: Architecture," 1995.
[12] E. Sirin, J. Hendler, and B. Parsia, "Semi-automatic Composition of Web Services using Semantic Descriptions," Web Services: Modeling, Architecture and Infrastructure workshop in ICEIS, 2003.
[13] E. K. Neumann, E. Miller, and J. Wilbanks, "What the semantic web could do for the life sciences," Drug Discovery Today: BIOSILICO, vol. 2, no. 6, pp. 228-236, Nov. 2004.
[14] The OWL Services Coalition, "OWL-S: Semantic Markup for Web Services," 2005. Last visited March. 2005. URL: http://www.daml.org/services/owl-s/1.0/owl-s.html
[15] C. Goble and D. de Roure, "The Semantic Grid: Myth Busting and Bridge Building," 16th Eur. Conf. Artificial Intelligence (ECAI), 2004.
[16] D. de Roure, N. R. Jennings, and N. R. Shadbolt, "The Semantic Grid: Past, Present, and Future," Proc. IEEE, vol. 93, no. 3, pp. 669-681, Mar. 2005.
[17] Román I., Roa L.M, Madinabeitia G, Millan A. "Introducing Guideline Management in the Healthcare Information System Architecture". Medical and Care Compunetics 4. In: Book.: IOS Pres, 2007. Editor: L.Bos et al. ISBN: 978-158603-751-2. pp 117-124.
[18] P. Clercq, J. Blom, H. Korsten, A. Hasman "Approaches for creating computer-interpretable guidelines that facilitate decision support" Artificial Intelligence in Medicine, Volume 31, Issue 1, pp 1-27
[19] M. Peleg, S. Tu, J. Bury, P. Ciccarese, J. Fox, R.A. Greenes, R. Hall, P.D. Johnson, N. Jones, A. Kumar, S. Miksch, S. Quaglini, A. Seyfang, E.H. Shortliffe, M. Stefanelli, "Comparing computer-interpretable guideline models: a case-study approach" J Am Med Inform Assoc 2003;10(1):52—68
[20] L. Ohno-Machado, J.H. Gennari, S.N. Murphy, N.L. Jain, S.W. Tu, D.E. Oliver, E. Pattison-Gordon, R.A. Greenes, E.H. Shortliffe, G.O. Barnett, "The guideline interchange format: a model for representing guidelines" JAMIA 1998;5(4):357—72
[21] J. Fox, N. Johns, A. Rahmanzadeh, "Disseminating medical knowledge: the PROforma approach" Artif Intell Med 1998; 14:157—81
[22] M.A. Musen, S.W. Tu, A. Das, Y. Shahar, "EON: a component-based approach to automation of protocol-directed therapy" JAMIA 1996; 3:367—88
[23] S.I. Herbert, C.J. Gordon, A. Jackson-Smale, J.L. Salis, "Protocols for clinical care" Comput Methods Programs Biomed 1995;48(1—2):21—6
[24] P.D. Clayton, T.A. Pryor, O.B. Wigertz, G. Hripcsak, "Issues and structures for sharing knowledge among decision-making. Approaches for creating computer-interpretable guidelines that facilitate decision support 25 systems: The 1989 Arden Homestead Retreat" In: Kingsland LC, editor. Proceedings of the Thirteenth Annual Symposium on Computer Applications in Medical Care. New York: IEEE Computer Society Press; 1989. pp. 116—21
[25] The Asgaard Project web site. Last visited March 2008. URL: http://www.asgaard.tuwien.ac.at/plan_representation/asbru_doc.html
[26] Corcho, O., Alper, P., Kotsiopoulos, I., Missier, P., Bechhofer, S. and Goble, C. An overview of S-OGSA: A Reference Semantic Grid Architecture. Journal of Web Semantics, 4(2), 2006.
[27] Ontogrid project web site. Last visited March 2008. URL: http://www.ontogrid.net/
[28] Foster, I., Kishimoto, H., Savva, A., Berry, D., Djaoui, A., Grimshaw, A., Horn, B., Maciel, F., Siebenlist, F., Subramaniam, R., Treadwell, J., Reich, J.V. The Open Grid Services Architecture, Version 1.5, Open Grid Services Architecture WG, Global Grid Forum, 2006.
[29] Special Section on BioGrid: Biomedical Computations on the GridIEEE. Transactions on Information Technology in Biomedicine. Volume: 12, Issue: 2, March 2008

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# Intelligent information system for treatment response monitoring and prognosis establishment on genital neoplasia patients

*Drd. Eng. Claudiu PLAISANU [a.1], Drd. Eng. Daniel NICULAE [b], Eng. Cristina OGESCU [b], Std. Cristina STEFAN [b]*
*[a] Project coordinator, SC IPA SA, Romania*
*[b] Project developers, SC IPA SA, Romania*

**Abstract.** Cancer is the second death cause in the majority of countries, including Romania. Nowadays the main cause of this very aggressive disease is still unclear, the study of cancer risk factors being the object of research. This article is presenting an intelligent virtual system, which has as a main purpose the monitoring of treatment response at genital area cancer patients as well as the assessment of their life expectancy and prognosis. The intelligent system is being developed by an undergoing national research project and will be implemented at The Oncology Institute of Bucharest, Romania.

**Keywords:** expert system, data acquisition, decision support, cancer, telomerase, prognosis

## Introduction

Currently, in the oncology field, negative aspects such as ignorance, diagnosis fear, lack of sanitary education are dominant. An important social and medical problem is the lack of decisive prevention and screening programs (finding cancer among the risk-free population), this fact leading to advanced disease states diagnosis. In this context, the treatment becomes only palliative and very expensive, generating extremely high suffering for the patient.

The acronym of the project presented in this paper is NEOSIM and its main purpose is that of improving the prognosis and life expectancy for patients diagnosed with genital area cancers. This will be achieved by designing and implementing a system which monitors the evolution of the disease, based on treatment response, evaluated through the changes in medical images, clinical and paraclinical parameters.

Besides, an innovative approach regarding the monitoring of disease evolution will be accomplished by tracking various parameters from genic expression category (for example - the level of telomerase which is an enzyme involved in DNA replication). This aspect gives the project an important degree of novelty, reflected by the fact that research on telomerase, as tumoral marker, represents an innovating element [5].

[1] Project coordinator, SC IPA SA, Calea Floreasca street, No. 169, Bucharest, Romania; E-mail: plaisanuc@ipa.ro

## 1. System architecture

The project presented in this paper will achieve the design and implementation of a virtual information platform, based on a decision support system with five main components:

- Oncological Warehouse;
- System Reasoning Core;
- NEOSIM Façade;
- Medical Knowledge Spring;
- NEOSIM Knowledge Interpreter;

Oncological Warehouse module consists of a medical knowledge database and it will have the role of storing the relevant information specific to oncology, gathered from specialists and experts in oncology and also from other medical sources. This module will use a variety of information, such as: data about patients, clinical and paraclinical parameters, genic expression category parameters (telomerase), imagistic data, facts, rules, solving methods, heuristics, complete and complex information about genital area neoplasia, clinical studies, etc.

System Reasoning Core module represents an inference engine, which is an application that holds the control knowledge. Through this engine, the medical knowledge database is exploited with the purpose of reasoning generation in order to obtain the required information for monitoring the evolutional state of neoplasia, for treatment adjustment and medical prognosis forecasting.

The dialogue interface (NEOSIM Façade) will allow communication of oncology specialists within the advising steps as well as on-line access of medical experts to the knowledge base. This module, together with Medical Knowledge Spring module, has also the role of adding and updating information into the system.

Medical Knowledge Spring module will be used for knowledge acquiring and it allows oncology specialists to insert the medical data in a form recognized by the system and, also, to facilitate the updating of complex medical data base;

The knowledge interpreting and explicative module (NEOSIM Knowledge Interpreter) has the purpose of explaining to medical personnel the information level of the intelligent system, the reasoning processes and the results obtained from advising sessions among oncology specialists. Also, this module will display the results obtained from the evaluation of changes suffered by analyzed parameters, the solution for treatment adjustment and prognosis;

Besides the modules described above, NEOSIM platform also contains a module that will ensure interoperability with existing information systems from the medical facilities where it would be implemented. A management section will be available for medical and IT experts.

The information system will be designed by using the latest technologies for medical information management. Technologies like semantic web and ontologies will be used, with the goal of increasing safety and integrity of data. The system will also be based on open standards like web services (SOAP, UDDI, and WSDL) or XML to ensure interoperability and integration of various applications and information systems that exist or will be developed in the future.

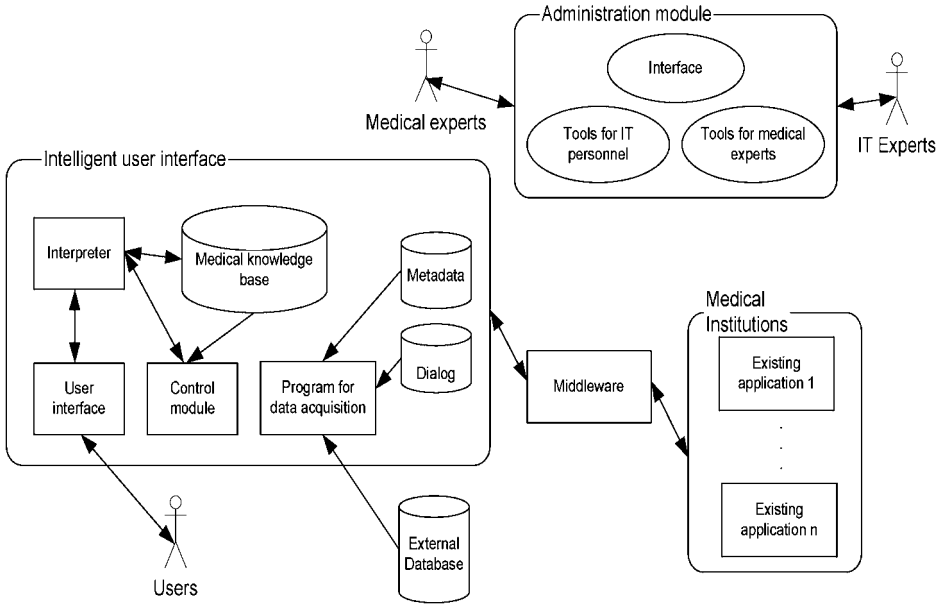


Figure 1 System architecture

## 2. Description of the user groups

The medical experts will access the information system to create descriptive models that will define the main characteristics of different types of genital area neoplasia. Treatment modification and prognosis are established on predefined sets of medical parameters, also generated by oncology experts.

The users, specialists in the oncology field, establish a dialogue with the system, through NEOSIM façade module, in order to optimize clinical decision by requesting additional information. Also, the system facilitates the dialogue and the advising among the oncology specialists through the elaboration of a virtual community.

The IT experts will access the system in order to monitor and manage, in real time, the execution environment of the system, from the technical-functional point of view.

## 3. Objectives

NEOSIM project would consist of complex activities, mainly fundamental research, application research and support activities. The project objectives are achieved during six important phases.

In the first phase, the project would create the conceptual models for medical decision and computerized models for medical data (clinical and paraclinical parameters, gene expression parameters, imagistic aspects)

Research generates system architecture, object orientated models for system function specification, identification models for the main characteristics of different

types of genital area cancers, a specific model for monitoring gene expression category parameters. These activities will be developed in the second phase of the project.

In the third phase, medical database and data knowledge structure are being developed. Specification of the intelligent monitoring, treatment change and diagnostic elaboration system (Oncological Warehouse, System Reasoning Core, NEOSIM Façade, Medical Knowledge Spring, and NEOSIM Knowledge Interpreter) will be defined. Also software specifications for adjacent modules will be created (administrative module, middleware, virtual community).

Phase four will come with the elaboration of programs and algorithms for information system component modules and programs and algorithms for intelligent monitoring, treatment change and diagnostic elaboration system.

The last two phases refer to the testing methodology and the scientific communications and demonstrations aspects. There will also be developed a presentation manual of the intelligent system.

The research activities that will be developed would lead to the following general objectives:

- Developing health informational frame by using modern technologies on a large scale.
- Improvement of knowledge assimilation and development through advanced services and technologies applied in health domain.

In order to accomplish this two main ideas, research would be conducted to more specific objectives, such as:

- Monitoring the evolution of genital area neoplasia and generating a prognosis on short/medium/long term, according to analysed variation of clinical and paraclinical parameters as well as symptomatology evaluation;
- Evaluation of tumoral marker levels in order to increase the prognosis accuracy;
- Disease appearance prevention – risk factors identification, early track down of potential patients, promoting more efficient manners of treatment.
- Biostatistics and clinical studies generation by specific analysis of medical data gathered by the system;
- Rapid access to specific resources for specialists and medical science students, training and knowledge improvement support.

## 4. Implementation of the intelligent system – outcome and main effects

It is essential to emphasize an fundamental consequence for the implementation of this type of intelligent system: it would made possible for the oncology doctor to answer the most common question that the suffering patients have – what is the life expectancy from the moment of diagnosis? In other words, one of the main effects of the system would be to ensure the patient that his life quality and prognosis are improved.

Another significant aspect is the high level of certitude in diagnosis assessment, due to computerized analysis of complex genetic parameters, especially the correct and

precise monitoring of telomerase level – an important indicator of tumoral presence and growth [5].

In the technical area, the project intends to use the most recent informational technologies meaning the web services, the ontologies, semantic web and advanced programming languages. This respects the newest development tendencies of informational society and the information access is not restricted by temporal or geographic barriers.

In the economy area, the project would generate a reduction of financial costs by increasing the efficiency of medical decision process.

In the social area, implementing the system would generate:

- Life quality and prognosis improvement for genital area cancer patients;
- Increasing quality and efficiency of health services;
- Reduction of medical errors by access to relevant medical data;
- Continuous professional build-up of medical specialists based on modern scientific knowledge acquisition;
- Education and research support in the medical field;

The project would also involve young specialists, besides experimented researchers, in order to improve their level of medical education and to familiarize them with a modern tool of diagnosis, prognosis elaboration and treatment. In this respect, the project would integrate the work of resident doctors, medicine students, and master and doctorate engineers, this aspect contributing to the development of medical informatics field.

## 5. Conclusion

It's utopian to claim that the oncologist doctor can be physically present by the patient around the clock, succeeding this way to monitor competently its state. Through the most modern aspect of medicine – telemedicine, or the medical virtual space – this thing is possible at this moment.

NEOSIM is a Romanian research project financed by national budget. The activities generated by the project will last three years and the results will be implemented in one of the most important oncological institutes from Romania. The project is in its second phase of development.

This project would create a complex virtual journal of disease evolution in which there will be included concrete data on the respective patient but, also, medical analysis, imagistic aspects as well as values of some clinical and paraclinical parameters. In the medical world, the research aims at discovering new methods for diagnosis and treatment. In the field of oncology an element of special interest is represented by life expectancy and prognosis. Through an intelligent information system it is now possible to continuously monitor important tumoral markers and other medical parameters in order to establish the most probable prognosis and the most adequate treatment.

Therefore, the complexity of the project comes from its quality to offer the oncology doctor a complex medical database on the patient, labour simplification with the help of modern informatics and telecommunication techniques, correct and complete medical information analysis based on a virtual interpretation algorithm. The

system also contributes to the improvement of patient's life quality by reducing the number of pointless travels to the medical facility and establishing correct treatment attributes and optimal administration moments.

## References

[1] Bredemeyer Consulting, Software Architecture and Related Concerns, 1999.
[2] H. Hofmann, H. Lehner, Reguirements Engineering as a success Factor in Software Projects, IEEE Software, 2001.
[3] Shelly Cummings, Current Perspectives in Genetics: Insights and Applications in Molecular, Classical, and Human Genetics, Brooks Cole, 2000.
[4] L.L. Gunderson, J.E. Tepper, Clinical Radiation Oncology, Philadelphia, 2000.
[5] Xueli Zhu, Rakesh Kumar, Mahitosh Mandal, Neeta Sharma, Harsh W. Sharma, Urvashi Dhingra, John A. Sokoloski, Rongshen Hsiao, and Ramaswamy Narayanan; Cell cycle-dependent modulation of telomerase activity in tumor cells; Proceedings of the National Academy of Sciences, Vol. 93
[6] Olivé, Antoni; Conceptual Modeling of Information Systems, ISBN: 978-3-540-39389-4, 2007.

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# Behavioural Compunetics

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# The Safe Implementation of Research into Healthcare Practice

Bryan MANNING[*] and Stephen BENTON[**]
*University of Westminster[*]*
*School of Informatics and*
*Centre for Business Information, Organisation, and Process Management*
*Westminster Business School,*
*University of Westminster*
*bryan.manning@btinternet.com*

*Business Psychology Centre[**]*
*University of Westminster*
*Department of Psychology*
*bentons@westminster.ac.uk*

**Abstract**: Miscommunication, misunderstanding and outright error have all played significance roles in triggering Adverse Events across the spectrum of health care delivery. As a means of countering these effects this paper outlines a twin track approach. This firstly focuses on developing a care pathway modelling approach both as the basis for better understanding of interdisciplinary process interaction, and also as a means of rapid access to relevant clinical knowledge. This is then set in the context of the human behavioural issues that can all too easily prejudice patient safety. It also explores the potential to apply the large body of knowledge and experience in risk management techniques applied to life critical decision taking under high stress conditions.

**Keywords:** Care Pathways; Information Access; Knowledge Transfers; Adverse Events; Risk Management; Behavioural Compunetics.

## Background

Despite the introduction of multi-disciplinary team working, the professions still maintain much of their traditional 'silo' centric approach to knowledge exchange across their specialist domain boundaries. Whilst Continuing Professional Development [CPD] requirements should ensure that appropriately validated new knowledge is properly disseminated within and between these domains, procedures to confirm its adoption in practice are in many instances missing. There also tends to be little in the way of formalised interdisciplinary exchanges, which can act to reinforce the 'silo' culture, within organisations, one that imprints itself across a wide range of systems [1].

Currently this effect is fairly well mitigated by clinical managements' use of procedures, guidelines and recommended best practice processes and pathways to establish performance standards as the basis of good governance. However problems

and adverse events have been shown by forensic studies to arise out of variability at the detailed level and in particular where there are hidden or unrecognised interdependencies between treatment practices by different professions. Professional judgment (e.g. diagnosis) and decision making (e.g. care intervention) are arguably the product of a dual process, one readily amenable to management/practice procedures with explicit communication and a second, more subjective, derived from accumulated and variable personal experience. While the relationship between these systems offers opportunities for enriched information processing it is clearly the case that it is also responsible for flawed shared judgement and false assumptions.

## 1. Care Processes

Healthcare providers also exhibit the same 'silo' approach displayed as by their constituent professions, however this is due to the need for all organisations to set boundaries that clearly delineate the limits of operations. The unfortunate consequence for patients is that their end-to-end care process threads its way across these domain boundaries with resultant changes both in organisations and professionals holding responsibility for their treatment.

The overall effect is that there is a lack of clarity of the likely sequence of events involved in resolving or ameliorating the patient's presenting conditions. The prevailing culture appears to consider that it is pointless to have to have even an approximate plan of action in view of the innate variability in the progression of either the illness concerned or its treatment.

However this is tantamount to saying that in other potentially hazardous domains, the use of navigation charts and flight plans are unnecessary, as they will not be followed to the letter – which is patently wrong and would be highly unsafe! As health care expands towards the remote domain, it will become imperative that the level of monitoring, information gathering, storage, sharing and analysis is at least commensurate with the best achieved within unit care today. As ICT systems, within and without institutions, augment and reshape aspects of care it is necessary that the full utility of information be realised within and between professions as technology reshapes care boundaries, form and related sequences.

The key issue is that whilst such representational charts fulfil the need for the point of reference for decision-making in these domains, their use is noticeably absent in the clinical domain. This defect is even more evident in the context of the complete cross-border 'patient journey' from one end of the overall process to the other. This transit not only crosses primary, hospital and community care organisational boundaries, but also many treatment stages, which may well be 'fenced-in' within departmental sub-domains settings, as shown below.

These stage boundary conditions involve achievement of target organisational or treatment outcome goals that act as 'gateways' to the next stage. These could be organisational transfers from ITU - to HDU – to wards; or clinical assessment – diagnosis – treatment outcomes/s – discharge – community needs assessment – and community care [See Figure 1].

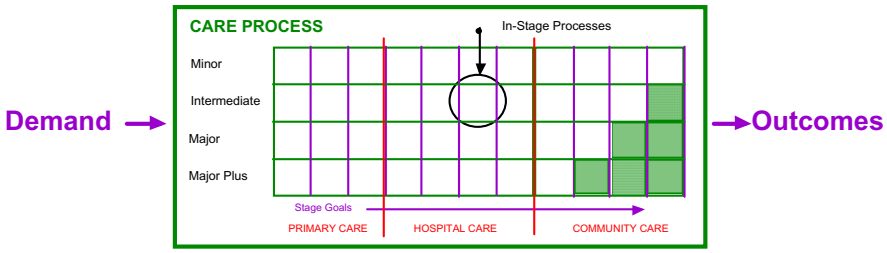


Figure 1. Care Process Stages

Case complexity adds a further dimension in that, whilst the 'gateway' goals are common, there are inevitably a series of step-changes in the level of treatment complexity in in-stage processes required. These follow the same pattern of minor, intermediate, major, and major plus sets used in surgery. These severity sets act as further domains, where transfers are driven by the level of care response required by changes in the patient's condition.

## 2. Care Process Pathways

High-level care pathways are generally used to identify all the major steps across the spectrum of complexity that are potentially involved in the treatment of a given condition [2], such as shown for Acute Myeloblastic Leukaemia (see Figure 2).

Whilst one of the more complicated conditions to diagnose and treat it illustrates at high-level only just how wide a variety of routes the 'patient journey' treatment sequence may take. Whilst this provides the starting point for gathering statistical data to support clinical governance and control procedures, it is not sufficient to provide the necessary insights into actual routes taken – both formal and experience-led - or the decision criteria used.

As ever the 'devil is in the detail', and emphasises the need to map formal in-stage processes at various levels of detail, dependent on the level of case complexity and the options available (see Figure 3). This will provide a sound foundation on which to tackle the problem of coping with experience-led process variability that invariably occurs in decision-making. Tacit knowledge derived from years of professional activity invariably leads to idiosyncratic process evolution around the formal norm, which generally remains hidden and yet contributes to variations in clinical outcomes [3].

The complexity of potential formal treatment options is well illustrated in the chemotherapy/bone marrow transplant care process pathway options shown below for Acute Myeloblastic Leukaemia. Here the four main routes each have major variability in-built in the initial two stages with 'switch-out/over' decision points where complete remission has not been achieved.

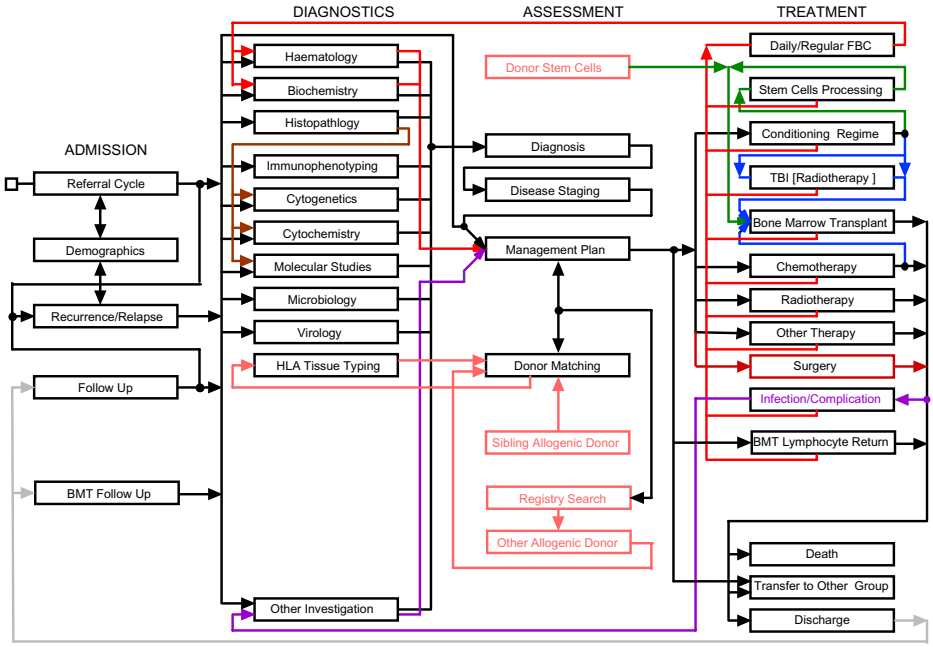


Figure 2. Acute Myeloblastic Leukaemia - Process Sequence

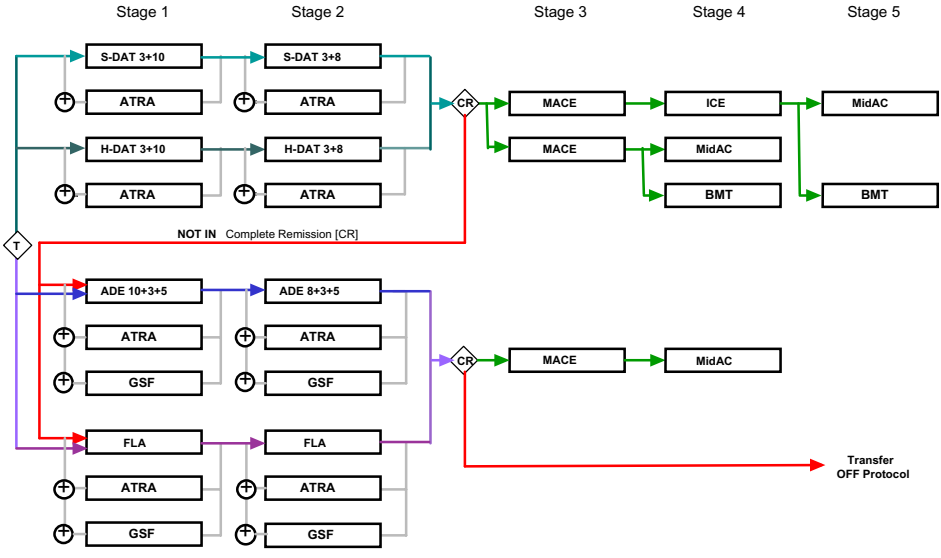


Figure 3. Acute Myeloblastic Leukaemia – A set of Treatment Sequence Options

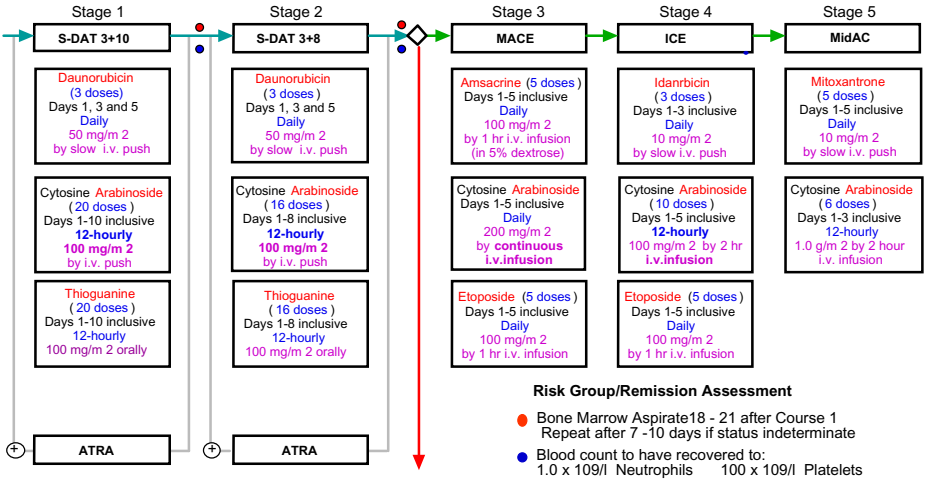


Figure 4. Acute Myeloblastic Leukaemia - S-DAT Sequence - Attached Knowledge

Whilst the potential for dosage variability is immediately obvious from the first route shown (see Figure 4), it also demonstrates the potential to attach and index knowledge to a process map.

This knowledge-indexing approach, together with appropriate version release controls would be central to providing latest validated clinical information to support decision taking by those in the 'front-line' of service delivery.

However, provision of such information alone will not ensure that it is used appropriately or at all. Its adoption into the everyday clinical working culture is ultimately dependent on delivering real, clinically desired benefits to professional practice and to resultant patient outcomes. As a result evidence of its latent worth and subsequent delivered value is essential to secure a successful transformation in attitude and uptake by all the professions concerned.

This evidence can only be gathered through much improved detailed knowledge of the current processes in use together with their limitations, deficiencies and attendant risks of errors or error producing conditions. The key to this lies in creating a widely acceptable feedback mechanism that makes negligible downside impact on clinical activities, and does not adversely affect or limit the use of professional judgement and experience

This can be achieved through an adaptation of the way the Electronic Patient Record [EHR] is created. The proposed approach centres on the use of well-structured Care Process Pathway maps as a means of semi-automatically logging events into the EHR.

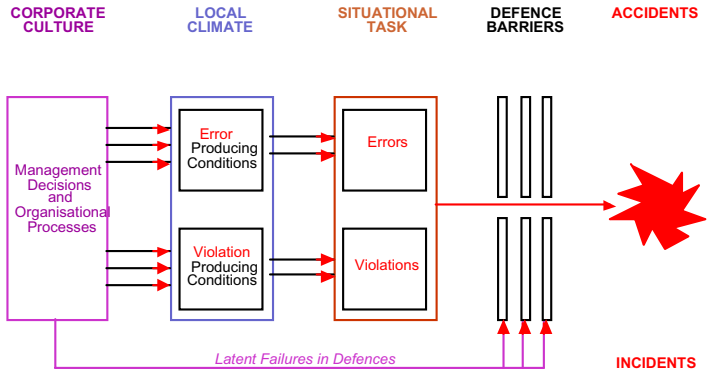


Figure 5. Adverse Events – Contributory Factor Chain

Its aim is to use the relevant pathway step together with the knowledge indexed to it as a means of updating the record. The essence of the approach is that updating would either entail adopting the recommended action and uploading its 'as is', adapting it to suit the circumstances, or choosing an alternative approach - effectively ignoring the recommendation - and entering the action taken as per current practice.

Automatically categorising all record updates in terms of the three types of action taken, viz: adopted; adapted; or ignored, would provide a direct profile of the clinician's responses to newly available knowledge. More importantly it could radically reduce record input workloads, provided the pathway correctly reflected the bulk of current practice, whilst not constraining or impacting professional autonomy.

## 3. Combating Adverse Events

The introduction of the proposed care process pathways approach would provide much greater transparency not only in governance terms, but also provide the basis for early identification of potential hazards and latent exposure to adverse event risks, as shown in Figure 5.

The risk of accidents or other incidents almost invariably result from a combination of clinical error producing conditions and/or violations of guidelines/procedures together with unidentified points of failure in defence mechanisms (see Figure 5). These are frequently compounded by a chain of unforeseen events that are often set in motion by a mixture of corporate and clinical cultural stresses.

Ultimately all organisations stand or fall as a result of how well their workforce is motivated and managed, of course given that they are appropriately funded. In order to continuously maintain high performance standards senior management not only have to strive to optimise service quality through on-going process and procedural improvement, but also by seeking to block or mitigate latent failures through appropriate defence mechanisms.

However, regardless of how well these organisational controls are designed, human attitudes and likely errors are the most difficult to predict and counter. Whilst an appropriate corporate culture is vital in setting the overall ethos, in specific terms

the creation and support of robust working relationships represents a core element in effective inter-disciplinary operational effectiveness. In practice major challenges persist in the inhibition of 'silo' effects and resultant disconnects between clinical and management professionals, as evidenced by the divergence of views generated by the government clinical governance programme [4].

Similarly effective interaction and mutually valued exchange of experiential knowledge within and between clinical domains, as well as support functions, should mitigate the chances of error producing conditions or procedural violations whilst under stress. The creation of a good trans-disciplinary working culture has already been established in the form of clinical team working in many care environments right down to the level of situational tasks.

Nevertheless, much remains to be done to understand the factors that conspire to trigger incidents especially where situational stress is concerned. It is interesting to note that whilst much effort has been expended on risk management in safety critical environments where life-threatening conditions can occur, little of this expertise has been transferred across into the care domain [5][6][7].

Another major contributory factor that lies behind this problem is the general lack of any clear visibility either of the processes and their interaction with the resources that enable them to proceed. This is particularly surprising when compared with sectors, where high stress-levels and threats to life are inherent; all base their risk management defence procedures on process-based modeling and analysis.

As healthcare is centrally reliant on experienced clinical human resources to deliver its care delivery processes, it almost inevitable that most adverse events stem from errors and omissions in the various supply chain processes, as typified by the dual process which underwrites knowledge transfer (see Figure 6).

Care delivery is naturally the core process enabled in turn by other sets of supply chains. Whilst the series of alternative routes, discussed earlier, outline the broad treatment process, they in turn are likely to involve a mixture of inter-related parallel processes carried out by care professionals from different disciplines, as shown below for a notional care stage.

Even though they may be operating as part of a multi-disciplinary team, a combination of the lack of a shared inter-disciplinary pathway plans, plus the professional 'silo' effect can result in a serious disconnect between the activity streams.

At best this may result in wasted effort; at worst it may negate the work of the other professions involved and trigger an adverse event. The key to avoiding these circumstances lies in identifying these points of interdependence [shown on red] and putting in place procedures to obviate or mitigate such potential disconnects.

Since the trigger for most adverse events result from human errors, often made under stressful circumstances, minimising and mitigating their effects is paramount. Whilst the deployment of appropriately skilled and experienced clinicians is central to enabling consistent high quality care to be delivered, ensuring that continuously evolving new clinical knowledge is absorbed into their working culture is vital.

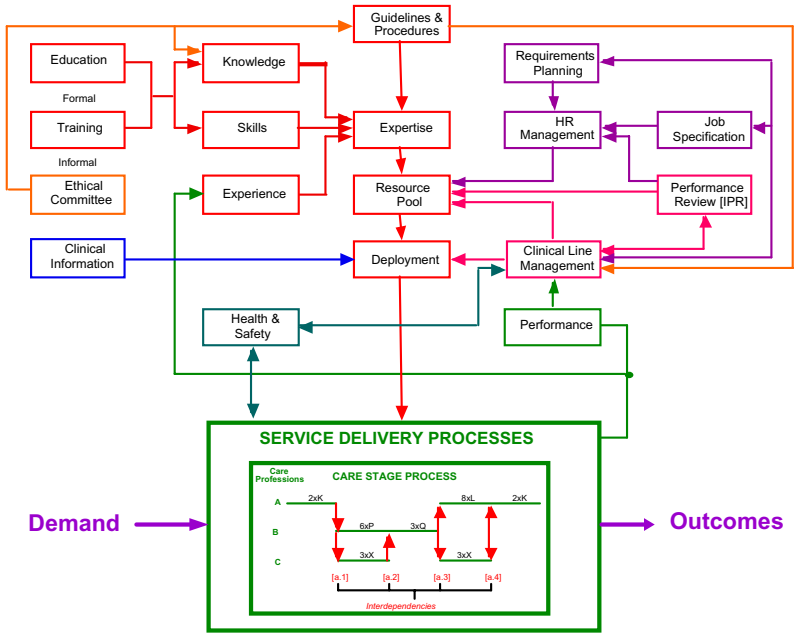


Figure 6. Clinical Human Resource Management Components

The success of the 'rolling' change process is ultimately determined by a well-balanced input from three main supply chains. Whilst subtly delivered professional development through effective knowledge transfer contributing to the growth of individual clinician's expertise is central to this, so is a controlled exposure to situations that help build up their experiential knowledge.

The second chain delivers a supporting framework to this development through the provision of guidelines and procedures, which provide the control mechanism needed to ensure best practice consistency. However at present this control process suffers from lack of day-to-day visibility of performance quality; no point of reference to identify significant deviations from currently evolving norms; little or no basis for timely, pro-active identification of treats or triggers of adverse events; and of necessity, reliance on post-event preventative action.

The final chain is more amorphous in that it delivers a wide range of different types of information – and by definition knowledge – in a variety of forms, ranging from the readily understandable though to the highly complex, difficult to assimilate and potentially error producing. Almost more importantly there are relatively few controls in place to ensure validity of content, or reduce latent ambiguities in its presentation.

Whilst reducing the error potential both within these individual chains and where they join to interact at the point of delivery of care is a decidedly non-trivial task, much can be achieved through the development of process mapping and monitoring techniques proposed earlier. The emergence of a far clearer picture of clinical practice processes will in turn provide the basis for identifying potential adverse event triggers and putting in preventive measures.

## 4. Implementing Change

Change can be viewed as abhorrent, especially if it is imposed. The remedy is to engage all sides in identifying the defects and discrepancies of the 'As Is" situation together with the benefits carefully managed change could deliver and resulting in a benefits 'roadmap' (see Figure 7).

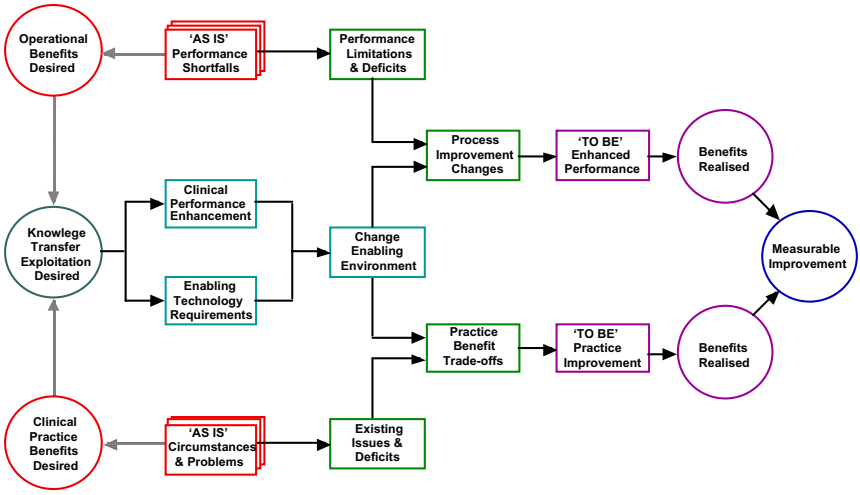


Figure 7. Benefits Realisation "Roadmap"

In essence the approach described earlier has outlined much of the potential route to be followed to reach the desired benefits of the "To Be" situation. Exploiting the full potential of newly available clinical knowledge requires the combination of process mapping methodology together with supporting technology to deliver the operational environment needed to enable changes in clinical practice to take place [8]. However for it to take root the benefits must be seen by all to substantially outweigh any perceived risks and disadvantages.

## 5. Measuring Change

In essence the implementation of changes in practice will be directly measurable as a by-product of the proposed simplification of the EHR updating process, where decisions to adopt a process step in a newly authorised option are a positive confirmation.

As significant changes in clinical practices result from new knowledge and are regulated by ethical committees or similar bodies, their authorisation procedures should ensure that current clinical process maps are updated though an appropriate change control process. A similar procedure would be followed under local clinical governance control in response to frequently used process adaptations.

Where a qualitative assessment of the relative worth of the impacts of changes in clinical practice is required the "radar plot" can be used (see Figure 8).

This uses a radial set of multiple assessment criteria with a common scale range. The area enclosed by linking the initial settings gives an immediate view of the scale and segmentation of the deficits [9]. Regular re-assessment plots reveal progress made towards an end goal as a result of any change process.

Whilst the example used demonstrates the principle in terms of an elderly patient's presenting circumstances and subsequent improvement as a result of multi-agency care, its applicability to a wide range of applications is evident. Its application to the impact of knowledge enabled process change merely requires the definition and agreement on an appropriate set of assessment criteria and any required segmentation.

Although its implementation would primarily be based on case group governance reviews, it has the potential to be a semi-automatic derivative of the proposed EHR updating process.

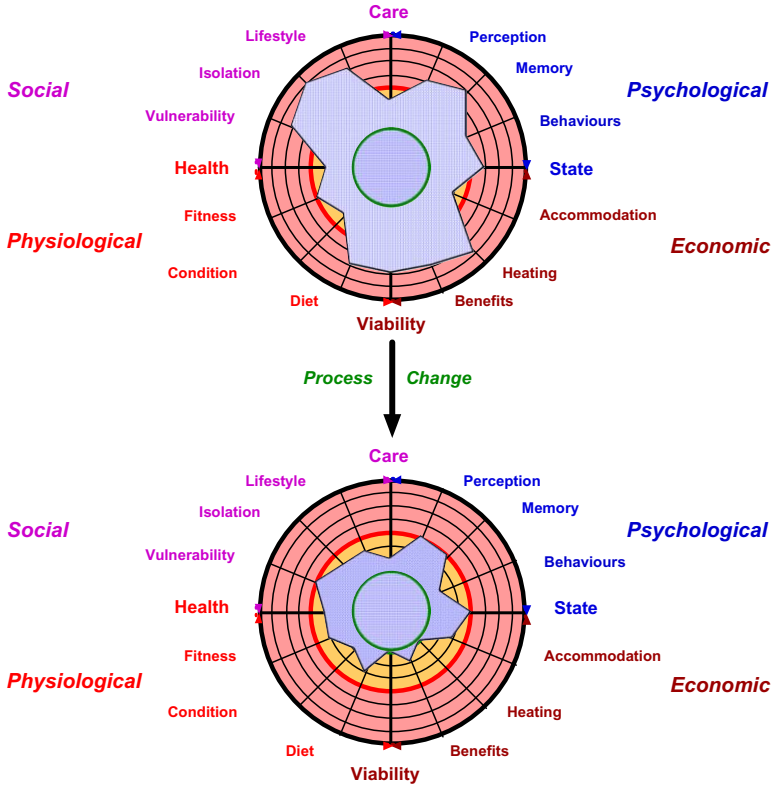


Figure 8. Process Change Impact "Radar Plots"

This paper has focused on the use of a unified "whole-systems" approach to inter-relate end-to-end processes; development and deployment of appropriate human resource skills and knowledge; within ever increasingly complex information systems, content and flows. If emergent ICT systems are to expand into the gap left by diminishing resources and escalating demands while also innovating improved care patterns, they will need to support and extend the interdisciplinary base for information exchange and utilisation.

## REFERENCES


[1] Gregory, K. (2005*) Implementing an Electronic Records Management System: A Public Sector case Study.* Records management Journal, Vol. 15, Issue 2, PP 80-85. Emerald Group Publishing Ltd.

[2] Schey, S.A. (2000) *Guidelines for the Care of Patients – Progenitor Cell Transplant Protocol:* Guy's & St.Thomas' Hospital NHS Trust [Bone Marrow Transplant Unit – Reference Manual]

[3] Welsh, I. And Lyons, C.M. (2001) *Evidenced-based Care and the Case for Intuition and Tacit Knowledge in the Clinical Assessment and Decision Making in mental Health Nursing Practice: An Empirical Contribution to the Debate.* Journal of Psychiatric and Mental Health Nursing. Vol. 8 (4), 299-305.

[4] Degeling, P.J., Maxwell, S. Ledema, R. and Hunter, D.J. (2004) *Making clinical governance work.* BMJ 2004;329:679-681 (18 September).

[5] Swain, A. D., & Guttman, H. E. (1983). *Handbook of human reliability analysis with emphasis on nuclear power plant applications*.. NUREG/CR-1278 U.S. Nuclear Regulatory Commission, (Washington D.C.), January 1984.

[6] Miller, D.P. and A.D. Swain, (1987) *Human Error and Human Reliability. Chap. 2.8* in G. Salvendy (Ed.), Handbook of Human Factors, New York: Wiley.

[7] G. Salvendy (Ed.), *Handbook of Human Factors*, New York: Wiley.

[8] Manning, B., McKeon Stosuy. M, Layzell B. (2005) *e-Care Coordination: An Inclusive Community-wide Holistic Approach* in: The Information Society: Emerging Landscapes. Springer June .

[9] Benton, S. and Manning, B. (2006) *Assistive Technology Behaviourally Assisted in:* Technology and Informatics 121: Medical Care Compunetics, Vol. 2. IOS press.

*Medical and Care Compunetics 5*
*L. Bos et al. (Eds.)*
*IOS Press, 2008*


# Finding the service you need: Human centered design of a Digital Interactive Social Chart in DEMentia care (DEM-DISC)

H.G. VAN DER ROEST [a], F.J.M. MEILAND [a], T. HAAKER [b], E. REITSMA [c], H. WILS [d], C. JONKER [a], R.M. DRÖES [a]

[a] *Departement of Psychiatry/Alzheimercenter, EMGO Institute, VU University Medical Center/Stiching Buitenamstel Geestgronden, Valeriusplein 9, 1075 BG Amsterdam, The Netherlands, hg.vanderroest@vumc.nl*
[b] *Telematica Instituut, Brouwerijstraat 1, 7532 XC Enschede*
[c] *Ericsson Telecommunicatie BV, Ericssonstraat 2, 5121 ML Rijen*
[d] *Waag Society, Nieuwmarkt 4, 1012 CR Amsterdam*

**Abstract:** Community dwelling people with dementia and their informal carers experience a lot of problems. In the course of the disease process people with dementia become more dependent on others and professional help is often necessary. Many informal carers and people with dementia experience unmet needs with regard to information on the disease and on the available care and welfare offer, therefore they tend not to utilize the broad spectrum of available care and welfare services. This can have very negative consequences like unsafe situations, social isolation of the person with dementia and overburden of informal carers with consequent increased risk of illness for them.
The development of a DEMentia specific Digital Interactive Social Chart (DEM-DISC) may counteract these problems. DEM-DISC is a demand oriented website for people with dementia and their carers, which is easy, accessible and provides users with customized information on healthcare and welfare services.
DEM-DISC is developed according to the human centered design principles, this means that people with dementia, informal carers and healthcare professionals were involved throughout the development process.
This paper describes the development of DEM-DISC from four perspectives, a domain specific content perspective, an ICT perspective, a user perspective and an organizational perspective. The aims and most important results from each perspective will be discussed. It is concluded that the human centered design was a valuable method for the development of the DEM-DISC.

**Keywords:** dementia, informal carers, digital social chart, customized information, care and welfare service

## Introduction

The Freeband User eXperience (FRUX) project is part of the Freeband Communication program, which aims to generate public knowledge in advanced telecommunication (technology and applications). The focus of the FRUX project is to design ICT services and service bundles, in particular in the health care and safety domain. The objective is

to improve our understanding of how to design ICT bundles that a) really matter to end users and b) are profitable for service providers and their partners and suppliers. The aim of the Health Care pilot within the FRUX project is to investigate and develop new innovative services to support elderly people with dementia who live in the community, their informal carers (family and friends that care for the patient) and professional carers.

People with dementia and their carers are experiencing a lot of problems as a consequence of the illness. The needs of people with dementia change and often increase in number during the process of the disease. Whereas in the early stages of the dementia it can be sufficient to support memory, in severe stages of the dementia full support on daily functioning is often needed. People with dementia are often assisted by caring family members and to a lesser extent by professional carers.

Innovative technology may play an important role in the field of care and support for persons with dementia and their carers as the field of dementia care faces a number of problems now and in the near future. These problems include, in the first place, the variation, fragmentation and continuous changing of care and welfare services in a region. Clients and referrers experience difficulties finding the services they need and therefore tend not to utilize the broad spectrum of available services. Possible consequences are: not receiving the specific care and support one needs, unsafe situations, social isolation of patients and frustration, overburden and illness of carers. Thus, the need for a more transparent, easily accessible and integrated offer of healthcare and welfare services is growing.

Another problem (or challenge) is the generally recognized need to create a continuum of flexible care and welfare bundles in every region in the Netherlands that dynamically meets the care needs and wishes of individual persons with dementia and their informal carers in the different stages of the disease. Understanding the gaps in the present offer, requires insight into the care needs and wishes of this client group and their informal carers, as well as an up-to-date overview of regional (and national) services. Recently, a first step was taken to collect this type of information in the Netherlands: a National Dementia Program (NDP) was developed which describes needs of the target group and examples of potential care offerings (Meerveld and others 2004). The aim of the NDP is to bring relevant care and welfare providers together, to signal problems in dementia care on a regional level and to make up solutions for these problems.

The addressed problems in the field of dementia care may be counteracted by a Digital Interactive Social Chart for DEMentia care (DEM-DISC). The DEM-DISC will be a demand oriented site for people with dementia and their carers, that is easy to use, easy accessible, and that contains customized information on national and regional healthcare and welfare services. From a recent state of the art review of ICT services, we know that there is no such proven effective ICT service in this field (Lauriks and others 2007). The existing social charts are typically quite static, generic, and often provide incomplete lists of addresses. The DEM-DISC operates at three levels:

- At a *micro level* to support with information advice in a user-friendly and context sensitive manner, by providing bundles of services (if relevant), thus counteracting the negative consequences of the fragmentation of services and to help people stay in their own home for a longer period of time with adequate services.

- At a *meso level* by stimulating the collaboration between care and welfare services and by detecting gaps in the continuum of services in a region
- And at a *macro level* by helping people with dementia to stay in their homes for a longer time, DEM-DISC will contribute to a delay of nursing home admission and consequently to a reduction in health care expenditure (Dröes and others 2005).

DEM-DISC is developed from four different perspectives: a domain specific content perspective (needs, offerings, information and advice), an ICT perspective (knowledge management and application), a user perspective (people with dementia, informal and professional carers) and an organizational perspective (necessary collaboration, governance and control, business modeling) (Dröes and others 2005). The aims and most important questions from each perspective will be discussed.

*Domain specific content perspective:* DEM-DISC aims to recognize specific needs of patients with dementia and informal carers and therefore will contain an elaborated set of needs, formulated in the words of potential users (patients, informal carers and professional referrers). To be able to compile this dataset and to inform users about available services tailored to their needs and personal situation, the following questions have to be answered:

1. What are the needs of community dwelling people with dementia and their informal carers and how do they formulate their needs?
2. Which care and welfare services are available to fulfill those needs?
3. Which characteristics of the patient, carer or care situation are related to preferences for using specific services?

*ICT perspective:* DEM-DISC aims to be accessible, anytime and everywhere and to provide the answers to needs by offering customized information on the available care and welfare services. This means that DEM-DISC should be available by the internet and should be able to connect specific service bundle(s) to specific (complex) needs that are expressed by users. The most important questions with respect to the ICT perspective are:

1. How can DEM-DISC be designed as a web application (requirements, technology) and what requirements are needed for the user interface when used by people with dementia and/or carers?
2. How can relevant context information be gathered in DEM-DISC?
3. How can user needs, context information and available services be matched in the system?

*User perspective:* From the perspective of the person with dementia and the informal carer, it is important that DEM-DISC provides them with information in a user friendly manner, that it supports carers in their task and that it gives users insight into the available care and welfare offer according to their needs. The main questions here are:

1. Do users find and use the information they search for in DEM-DISC and is this information perceived as understandable, useful, up-to-date and sufficiently customized?
2. Does DEM-DISC have an impact in the daily lives of the people with dementia and their informal carers? Does it contribute to their quality of life,

does it reduce the number of experienced unmet needs and does it alleviate the care giving task and burden?

*Organizational perspective:* A viable exploitation of DEM-DISC in the future requires extensive collaboration and coordination between care and welfare organizations that participate in DEM-DISC. A business model needs to be developed that describes how organizations can cooperate and how legal boundaries and financial arrangements can be taken into account in DEM-DISC. The most important questions for the organizational perspective of DEM-DISC are:

1. What is the impact of health specific legislation and current organizational and financial arrangements on the options for business models and service bundling?
2. Is it possible to link DEM-DISC with actual service delivery in the future (digital shop for care and welfare services)?
3. What viable business models exist for DEM-DISC?

## Method

A human centered design was used to develop DEM-DISC. Common practice when using this method is to involve potential users or domain experts in the developmental process for obtaining user requirements and to evaluate and adapt the technology in small scale tests or a pilot study with potential users. Different methods were used to collect information for the development of a user friendly and useful DEM-DISC. A similar approach was used by Sixsmith and others (2007) to develop a technology wish list to enhance the quality of life of people with dementia.

The FRUX Health Care Pilot has been approved by the medical ethical committee of the VU University medical center.

### *Domain specific content perspective*

In order to gain more knowledge about the needs of people with dementia a systematic literature review was accomplished (Van der Roest and others 2007a) and a large scale survey on (unmet) needs in dementia among 236 community dwelling people with dementia and 322 informal carers (Van der Roest and others 2007b, Van der Roest and others in press). Background characteristics were inventoried and met and unmet needs of the people with dementia as expressed by themselves and by their informal carers. Descriptive analyses were performed and correlations between needs and background characteristics of people with dementia and informal carers were investigated.

For the formulation of the needs, wants and demands in DEM-DISC, the National Dementia Program (NDP) was utilized. The NDP describes fourteen problem areas in dementia as formulated by informal carers (Meerveld and others 2004). For our project we focused on five NDP areas. The needs that were inventoried in the large scale survey (Van der Roest and others 2007b, Van der Roest and others in press) were transformed according to the wordings of the NDP problem areas in order to make them recognizable for the users (informal carers). In DEM-DISC users can access a question tree that leads from needs to wants to concrete demands, in order to arrive at the specific demand description that expressed their felt need best (see Figure 1). Three

health care professionals were asked to criticize the used terminology during interviews in which the descriptions of needs were presented.

To build up a comprehensive, up-to-date dataset on offerings for DEM-DISC, the available care and welfare offer for people with dementia and carers in two districts in Amsterdam (Amsterdam Zuid and Amsterdam Zuideramstel) was inventoried. Data were restricted to the five need areas that were selected from the NDP. This information was collected by consulting paper guides, brochures, information on the internet and by interviewing three health care and welfare professionals working in the region. To enable DEM-DISC to provide customized information, service features with regard to product, personnel, price, place and promotion, according to the marketing model of Kotler (1980) were inventoried.

To relate user characteristics to care needs, data from the large scale survey were analyzed.

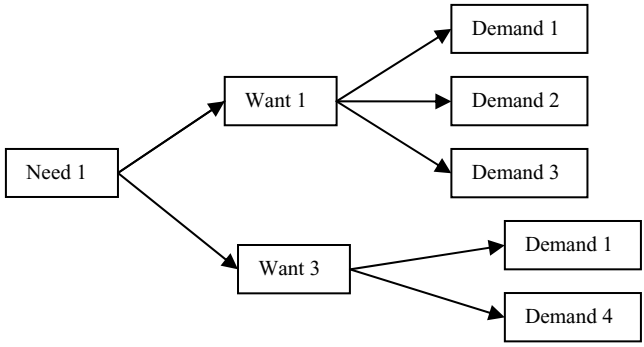


**Figure 1.** Question structure in DEM-DISC: Needs, wants and demands

*ICT perspective*

To be able to produce service bundles in DEM-DISC that provide customized answers to expressed needs, a service ontology was developed based on earlier research on service bundling. The ontology selects services based on their outcomes (demand driven), which is rather new in this field (Baida 2006). A main advantage of ontologies is that they can be represented in a machine-interpretable form, so that software can use them to reason about a domain, in this case: about customer needs and available services. The validation of the ontology was an iterative process. Service bundles were generated with an algorithm that uses the underlying service ontology as basis and were evaluated by domain experts on two points, 1) whether the service bundle offer a good solution to the demand and 2) whether all suitable solutions (service bundles) were generated.

*User perspective*

Potential users and domain experts participated in different phases of the development process.

*Phase 1:* In a workshop with potential stakeholders, professional and informal carers and researchers, three groups discussed the user requirements of DEM-DISC (Hulstijn and others 2005). The informal carer perspective, person with dementia perspective and domain expert perspective were discussed in separate groups. Discussion points in these groups were: how people would pose the system questions? Does DEM-DISC have to give insight into earlier and/or future needs? How should care advice be presented in DEM-DISC and how will DEM-DISC remain appealing to users? Based on the requirements that were agreed upon, a first prototype of DEM-DISC was developed.

*Phase 2:* In a workshop with three health care professionals preliminary designs of the user interface and the expert interface were presented and discussed. The professionals were asked to evaluate the terminology used in DEM-DISC user interface and to give their opinion on the design of the expert interface.

*Phase 3:* A demonstrator of DEM-DISC was tested among five informal carers of people with dementia in a small scale test (Meiland and others 2007). The informal carers were recruited from Meeting centers for people with dementia and informal carers and from the large survey on needs in dementia (Van der Roest and others 2007b, Van der Roest and others in press). The duration of the tests was at maximum three hours, all tests took place at the Valerius clinic and during these tests an interviewer, an observer and a technician were present. All tests started with an inventory of background characteristics of the informal carer and the person with dementia he or she cared for. Subsequently participants received a short introduction on DEM-DISC and were invited to explore the DEM-DISC website. Then participants were asked to perform a maximum of five tasks (this number depended on the computer skills of the individual participant and the time it took to fulfill the tasks) (see Figure 2). A task consisted of trying to find a satisfactory solution for a specific need by using DEM-DISC. After each task questions were asked (how did they accomplish the task, opinion on usefulness of the provided solution and user friendliness of the system) and observations were reported on. To record system reactions and to log all actions of participants a specific logging tool was used (TUMCAT, Vermeeren and Kort 2006). The tests ended with a questionnaire conducted by the researcher on usefulness and user friendliness of DEM-DISC and questions regarding the input and acceptability of entering personal information into the system. To evaluate the first demonstrator of DEM-DISC descriptive and qualitative analyses were performed. Based on the results of the

**Figure 2.** Setting small scale test

small scale tests, DEM-DISC was further improved.

*Phase 4:* The improved DEM-DISC demonstrator was evaluated by three health care professionals. During separate sessions the professionals were introduced to DEM-DISC and were invited to explore the site (user interface). During the sessions the professionals were asked to think out loud and to give their comments on the user interface (user friendliness and usefulness) and the content. During all sessions two researchers and a technician were present. Some of the problems mentioned by the professionals during the sessions were solved immediately by the technician. All comments were written down and discussed afterwards with the technical developer and the researchers.

*Phase 5:* During the further development the researchers, domain experts, performed several tests on DEM-DISC themselves. During these tests problems regarding the user friendliness or usefulness of both the user interface and expert interface, the content and the ontology were identified and discussed with the technical developers in order to improve DEM-DISC from an end-user point of view. The researchers were also responsible for the content of DEM-DISC. Issues with regard to updating information and modifying DEM-DISC were discussed with the developers throughout the whole process.

| Business model | Provider | User | Description |
|---|---|---|---|
| Commercial model | Commercial party | General public | All providers are allowed to provide information on their services, a quality standard should be applied. Exploitation cost could be covered by revenues from sponsors and advertisers. |
| Community model | Patient or informal carer community | General public | The community will be an important provider of information on dementia and specific care and support alternatives, as well as care providers that meet specific quality standards. The quality of information is important. |
| Government model | Governmental institution | General public | The aim is to create transparency and enhance competition between service providers. The quality of provided information can not be guaranteed. |
| Provider model | Group of care providers | General public | Services of network partners and complementary ones will be provided. |
| Insurer model | Insurance company | Own customers | Services provided are likely to be biased or limited, for the preference of the insurance company. |

**Table 1.** Alternative business models for DEM-DISC (De Vos and others 2008)

*Organizational perspective*

There are numerous potential stakeholders for DEM-DISC. To study what business model is preferred to exploit DEM-DISC, 14 stakeholder representatives with different backgrounds were interviewed (Moen 2006, De Vos and others 2007, De Vos and others 2008). The organizations involved were care providing organizations ($n$ = 6), governmental organizations ($n$ = 3), an insurance company ($n$ = 1) and interest groups

($n$ = 2). Five alternative business models were developed and presented to the representatives (see Table 1). In two series of interviews and workshops they were asked amongst other things for their opinion on these models, on the perceived added value of DEM-DISC for users and on potential benefits for their organization.

## Results

*Domain specific content perspective*

In the study on needs, most experienced unmet needs by people with dementia and their informal carers were in the domains of memory, information, social company, psychological distress and daytime activities (Van der Roest and others 2007b, Van der Roest and others in press). The five problem areas of the NDP that match with these needs were specified in seven general questions in DEM-DISC (the problem area 'What is the problem and what can help' was specified in three sub questions, see Table 2). By choosing one of the questions at the start, users are helped to specify the need. The architecture of the question tree in DEM-DISC is build in such a way that users are guided from general needs to more specific wants or concrete demands (see Figure 1).

| NDP domain | Terminology in DEM-DISC |
|---|---|
| Feeling that something is wrong, sense of unease | – I want to get rid of the feeling that something is off |
| What is the problem and what can help | – I would like to know what is going on<br>– I would like to know what can help for the person with dementia<br>– I would like to know what can help for the informal carer |
| Having to face everything on your own | – I would like to know what can help, so that I am not on my own |
| Avoiding contacts | – I want help with maintaining social contacts |
| Can not cope anymore | – I want help, because I can not cope anymore |

**Table 2.** Selected need domains and terminology for DEM-DISC

The relevant information on available care and welfare services for the two districts in Amsterdam (Amsterdam Zuid and Zuideramstel) was added into the database of DEM-DISC and finally services were matched to the relevant demands, according to the ontology.

54 Services were filed in the demonstrator of DEM-DISC. All services were characterized by the following features: product, personnel, price, place and promotion (the 5 P's by Kotler (1980)).

To enable DEM-DISC to generate customized and tailored advices several background and context characteristics of people with dementia and informal carers were related to the (number of) experienced needs by people with dementia and their informal carers, i.e. type and severity of dementia, living situation, carer-patient relationship, gender and age of informal carer and the subjective burden experienced by the informal carer (Van der Roest and others 2007b, Van der Roest and others in press).

*ICT perspective*

The validation of the ontology with domain experts was an iterative process. The generated service bundles were presented to domain experts. If a proposed service bundle was judged negatively or if domain experts missed suitable service bundles, it was analyzed why this occurred. In all these cases the shortcomings were due to wrong modeling, inaccurate production rules (considering demands/resources while neglecting to consider their properties) or wrong modeled service dependencies. These defects were corrected and new service bundles were generated. After the third iteration all generated service bundles were seen as suitable solutions and all desired service bundles were generated (Baida 2006).

*User perspective*

*Workshops*

During the workshop with possible stakeholders, professional and informal carers and researchers, several user requirements were advised. The main requirements and the implemented solutions were:

R1. The content should be general as well as personalized. Solution: A menu option to insert personal information was designed. With information on age, zip code, day or evening availability and whether transport is available, personalized information within DEM-DISC is generated.
R2. Keep the threshold for use as low as possible. Solution: DEM-DISC is designed as a web based application, with a simple interface and clear structure in which information can be found by a free search function or by a question tree.
R3. DEM-DISC should use existing databases. Solution: DEM-DISC refers to/links to information in existing systems, e.g. available websites of care and welfare organizations.
R4. Do not design just an information system, but support (online) contact between users (fellow sufferers, professional carers, support system). Currently this possibility is not developed for DEM-DISC.

The three health care professionals in the workshop on the user and expert interface brought up some questions/bottlenecks with regard to the expert interface in the future.

- Who will be the domain expert(s) that manages DEM-DISC? One person or several parties?
- Is every supplier allowed to store data in DEM-DISC? And what are the consequences for quality and uniformity of stored information?
- Who will guarantee the quality of the information? Does DEM-DISC require an independent person or organization that conducts this quality control?
- How exhaustive should information in DEM-DISC be? How will the information be described?

*Small scale test*

During the small scale test respondents' attitudes were not explicitly positive or negative toward the usefulness, user friendliness and satisfaction of DEM-DISC (Meiland and others 2007). Data from the small scale test resulted in judgments and advice on adaptations of the interface. These were categorized in five aspects: system, functions, content, interaction and behavior and design (see Table 3 for main results).

| Aspect | Recommendations |
|---|---|
| System | – develop a caching strategy |
| Functions | – improve the search function<br>– improve given advices<br>– add a personal page<br>– add new functions |
| Content | – adapt terminology and present it to other readers<br>– improve the introduction text on DEM-DISC as an information system<br>– change the order of standard questions<br>– provide complementary information on services by making links to the websites of these organizations available |
| Interaction and behavior | – make the questioning process tangible<br>– present services orderly |
| Design | – advices on font types<br>– use more colors to make DEM-DISC appealing and user friendly<br>– consider an introduction on each page<br>– consider adding organization logos by the links to these organizations<br>– improve the design of several pages |

**Table 3.** Main conclusions of the small scale test (Meiland and others 2007)

DEM-DISC was adapted according to the recommendations made in the small scale test and the database was extended with more services. The adapted version was tested among professional carers. They mainly commented on the lay out (font size, colors, representation of service bundles). A starting page with an explanation on DEM-DISC was added to improve its user friendliness. DEM-DISC was also extended with a new function, i.e. regularly updated news items on dementia. This was positively judged by the professionals. As a consequence of the evaluation erroneous content was changed and unclear terminology was adapted.

In the course of the process the researchers tested the user interface and various adaptations were made on content, layout, interaction and functions. The researchers also acted as domain experts and tested the expert interface. Due to bugs in the system and to insufficient caching, the expert interface was unstable and parts of the database were lost. In the course of the development process the decision was made to use a basal and more reliable database to fill DEM-DISC, based on Excel. A user friendly interface that could be used by domain experts in the future still has to be developed.

*Organizational perspective*

The consulted stakeholder representatives did not have a unanimous preference for one business model (Moen 2006, De Vos and others 2007, De Vos and others 2008). During the interviews and workshops the community model and the governmental

model were considered to be the most viable options to exploit DEM-DISC, the insurer model and the provider model were less preferred, whereas the commercial model was assessed as not viable at all. Commercial parties may have interests that conflict with that of DEM-DISC. The community model was favored because patient or informal carer communities represent the interest of the patient and are independent, but the professionalism of these communities was doubted by the interviewed representatives. Because governments have a general interest in the well being of elderly people, this model was also favored. However the expected focus on short term politics weakened the positive attitude.

The quality of provided information is seen as an important success factor for a business model by the interviewed stakeholders, but an acceptable distribution of roles is considered of less importance. The parties are more ambiguous in their opinions about acceptable distribution of profits and clear network strategies.

*Description of the first prototype of DEM-DISC*

The first prototype of DEM-DISC is available on the internet with Mozilla Firefox. The user interface is kept simple with even colors and consists of three parts: On the left side the menu is situated, the main content of DEM-DISC is displayed in the middle of the page and on the right side a map of the Netherlands is presented and several dementia related websites (see Figure 3). On the top of the page a search field is provided in which keywords can be entered. The DEM-DISC contains information on 229 care and welfare services in two districts in Amsterdam.


Figure 3. DEM-DISC homepage

*Menu options*

The menu contains six buttons: ‘How does it work?’ (homepage), ‘Frequently asked questions’, ‘News’, ‘Tailored information’, ‘Helpdesk’ and ‘Colophon’.

*‘How does it work?’.* This gives information on DEM-DISC, on how to search in DEM-DISC and how ‘Tailored information’ works.

*'Frequently asked questions'.* Seven general questions are presented to the user. In three steps users can specify their question or problem by going from a general need to a specific demand. For the selected demands relevant information on services is shown, including information on required resources (f.i. an care indication), required services, optional services and conflicting services. If relevant for a demand, it is possible to select preferences with regard to the service provision (internet, phone, group, individual conversation), information type (general, specialistic), location (own home, outside) and place (care facility, community center, elsewhere).

*'News'*. This option provides regular updates on news with regard to dementia.

*'Tailored information'*. By logging into the system, users can enter their personal page. On this page information can be entered about both informal carer and the person with dementia on age, zip code, day or evening availability and whether transport is available. This input personalizes the information on the care and welfare offer that DEM-DISC provides to users.

*'Helpdesk'*. Contact information of the helpdesk is provided in this section in case users experience problems.

*Map and websites*

On the map the separate provinces of the Netherlands are displayed. By selecting a specific province, a list of websites that provide information on dementia, care, legislation and financial issues in that particular province is shown. National websites on these issues can also be selected. Links to the websites are opened by clicking on the titles.

## Discussion

Using a human centered design during the development process of DEM-DISC has proved its merit. The involvement of people with dementia, informal carers and health care professionals by means of interviews, workshops and test sessions provided a substantial amount of high quality information and input for DEM-DISC. Many research questions from the different perspectives could be satisfactorily answered.

*Domain specific content perspective*

Interviewing a large group of community dwelling people with dementia and informal carers provided insight into their needs and the way in which they express their needs. It also gave insight into which needs are related to personal characteristics. While people with dementia and their carers informed us on their needs, professional carers gave useful feedback on the proposed formulation of these needs in DEM-DISC and provided additional information on relevant care and welfare services. Altogether, this information enabled us to compose a comprehensive and realistic dataset of needs in dementia and available care and welfare services that enables DEM-DISC to provide users with customized information on the available services.

*ICT perspective*

Modeling user demands and services in the field of dementia care according to an algorithm based on a service ontology proved to be feasible for DEM-DISC (Baida 2006). Using this ontology in DEM-DISC and making DEM-DISC available online, enables informal carers to judge if the presented customized service bundles actually meet their demands. The opinion of informal carers on the proposed service bundles and interface will be further evaluated within a pilot study in which, among other things, the user friendliness of the first prototype of the DEM-DISC will be evaluated. This pilot study is conducted in the period of December 2007 until March 2008.

*User perspective*

During the small scale tests with informal carers and test sessions with professionals, a lot of information on user friendliness and usefulness of DEM-DISC was gathered. Although the informal carers that took part in the small scale tests did not have an explicit positive or negative attitude towards the usefulness and user friendliness of the application, they gave many tips and comments on how to improve DEM-DISC. This resulted in the first prototype of DEM-DISC: A system that has a user friendly interface and that contains a broad offer of services and is able to advise personalized bundle(s) of services for specific demands.

As mentioned before, this first prototype will be tested in the final stage of the FRUX project. DEM-DISC will be installed in the homes of informal carers and they will have the opportunity to use DEM-DISC for two months in their own environment. Besides the user friendliness and the usefulness, the impact on daily life will be investigated. Results of this study will be used for further development and valorization of DEM-DISC.

*Organizational perspective*

The workshops and interviews with stakeholder representatives did not result in a unanimous preferred business model (Moen 2006, De Vos and others 2007, De Vos and others 2008). Although most stakeholders preferred the community model, the governmental model was also evaluated positively. Whereas quality of information was highly valued by the stakeholders, it was considered most feasible to combine business models for DEM-DISC, like the government model and the provider model. A business model for DEM-DISC should be chosen very accurately, since for the wellbeing of the users it is highly important that all relevant parties cooperate and coordinate their services intensively, and no parties are excluded. The choice for a business model will also determine the requirements of the expert interface. For example, decisions on single or multiple entry points for information entry, authorizations and methods to obtain uniform and up-to-date information will partly depend on the selected business model.

Though the human centered design offered DEM-DISC many benefits, we also experienced some disadvantages using this design strategy.

Using the human centered design in developing ICT solutions for this target group of users proved very time consuming, because of the iterative process required and the involvement of users in different phases of the developmental process. For instance, the

need survey took a year and the user and expert workshops as well as the recruitment of users for the small scale tests also demanded quite a lot of organization time of the researchers. Unfortunately, due to time constraints of this three year project and delay in the technical development of DEM-DISC, we were therefore only able to do one small scale test on the first demonstrator of DEM-DISC and were unable to test the more advanced version with users before the start of the final pilot study. The first prototype of DEM-DISC is designed to serve informal carers of people with dementia. The majority of them is aged above 55 years. Especially most of the elderly informal carers are currently not very experienced in computer use. From this point of view it was felt important to include many informal carers in the design process, in order to obtain a better understanding of the user friendliness and usefulness of DEM-DISC for this group. However, this proved difficult due to the nature of the target group: Although the majority of the approached informal carers supported the idea of DEM-DISC, only a few volunteered to participate in the project. The main reason was that many informal carers experienced high levels of burden, and had limited or no computer skills. Since the next generation of elderly will be more familiar with computers, this offers great potential for web based information systems, such as DEM-DISC, in the future and will make the application of human centered design approaches easier.

The FRUX Health Care pilot ends in March 2008. The final results of the DEM-DISC pilot study will be published on the project website, http://www.freeband.nl, in international publications and on (inter)national congresses.

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## References

[1] Meerveld J, Schumacher J, Krijger E, Bal R, Nies H. *Landelijk Dementieprogramma.* Nederlands Instituut voor Zorg en Welzijn / NIZW, 2004.

[2] Lauriks S, Reinersmann A, van der Roest HG, Meiland FJ, Davies RJ, Moelaert F, Mulvenna MD, Nugent CD, Dröes RM. Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews* **6** (2007), 223-246.

[3] Dröes RM, Meiland FJ, Doruff C, Varodi I, Akkermans H, Baida Z, Faber E, Haaker T, Moelaert F, Kartseva V, Tan YH. A Dynamic Interactive Social Chart in Dementia Care; Attuning demand and supply in the care for persons with dementia and their carers. *Studies in Health Technology and Informatics* **114** (2005), 210-220.

[4] Sixsmith AJ, Gibson G, Orpwood RD, Torrington JM. Developing a technology 'wish-list' to enhance the quality of life of people with dementia. *Gerontechnology* **6** (2007), 2-19.

[5] Van der Roest HG, Meiland FJM, Maroccini R, Comijs HC, Jonker C, Dröes RM. Subjective needs of people with dementia: a review of the literature. *International Psychogeriatrics* **19**(2007a), 559-592.

[6] Van der Roest HG, Meiland FJM, Comijs HC, Derksen E, Jansen AP, van Hout HPJ, Jonker C, Dröes RM. *Subjective and objective needs of people with dementia living in the community.* 17th Conference of Alzheimer Europe: The Sound of Silence. Estoril Portugal. May 10-12, 2007b.

[7] Van der Roest HG, Meiland FJM, Comijs HC, Derksen E, Jansen AP, van Hout HPJ, Jonker C, Dröes RM. What do people with dementia need? Do they agree with their carers? In press.
[8] Kotler P. *Principles of marketing.* Englewood Cliffs, N.J. 07632: Prentice-Hall, Inc., 2008.
[9] Baida Z. *Software-aided Service Bundling. Intelligent Methods & Tools for Graphical Service Modeling* [dissertation]. Vrije Univerisiteit, 2006.
[10] Hulstijn J, Haaker T, Huisman E, Meiland F, Slagter R. *DEM-DISC: Zicht op zorg rond dementie.* Report on the FrUX symposium "DEM-DISC: Zicht op zorg rond dementie" November 24th, 2005, De Waag, Amsterdam. Report nr FRUX/D2.6.14-II, 2005.
[11] Meiland FJM, van der Roest HG, Hooreman S, Wils H, Kort J, Dröes RM. *Evaluatie van de DEM-DISC.* Amsterdam: Freeband FRUX project; Report nr FRUX/D3.6.6-II, 2007. Internal report.
[12] Vermeeren APOS, Kort J. *Developing a testbed for automated user experience measurement of context aware mobile applications.* Position paper for the COST 294 workshop: User Experience - towards a unified view. NordiCHI2006, Oslo Norway, October 14th, 2006.
[13] Moen S. *A viable business model for 'DEM-DISC'. Which organizational arrangements may lead to a viable business model for 'DEM-DISC'?* Report nr FRUX/D.2.9-III, 2006.
[14] De Vos H, Haaker T, Moen S. 2.9 *A priori assessment of business models. Exploration of business models for DEM-DISC.* Report nr FRUX 2007/D2.5b, 2007. Internal report.
[15] De Vos H, Haaker T, Dröes RM. From prototype to exploitation: organizational arrangements for a Personalized Dementia Directory. In: Bouwman H, de Vos H, Haaker T, editors. *Mobile service innovation and business models*. Springer Verslag, 2008.
[16] DementieWijzer. Vraagbaak voor zorg- en welzijnsdiensten. http://www.dementiewijzer.nl, 2007.

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# The Doctor-Manager Relationship: A Behavioural Barrier to Effective Health Care?

Heather TAYLOR and Stephen BENTON
*Business Psychology Centre*
*University of Westminster*
*London*
*U.K.*

**Abstract:** The National Health Service (NHS) is a huge and complex organisation. Within it, acute Hospital Trusts operate within a range of constructs determined by central Government. Organisational success is measured against rapidly changing frameworks of standards and targets. The Griffiths report [1] signalled a perceived shift away from the professional autonomy of clinicians, towards general management systems. This resulted in tension between those responsible for delivering the Government's broader health agenda, and those driven by a desire to directly care for patients.

## Introduction

This study explored the principal drivers for doctors and managers in the NHS with the aim of determining whether there is scope to achieve alignment of aspirations (and resultant partnership working), to the benefit of the organisation and, hence, to the benefit of patients.

The study found that doctors and managers possess a range of shared interests, and share frustrations regarding the national NHS agenda. However, the potential for alignment is often blocked by the presence of historic bias, a lack of mutual respect, misperception, antagonistic assumptions, and a lack of belief in the 'potential' for autonomy as structured by these imposed organisational constructs.

## 1. Models of Organisational Success and Business Psychology

Whilst all businesses will define success according to a range of bespoke organisational objectives [2], a review of the literature relating to the broad concept of achieving organisational success through application of the principles of business psychology, indicates a necessity to:

- unite employees behind a vision, with clearly defined aspirations and goals [3];
- apply a mutually respectful system of principled negotiation [4];

- create a culture of effective team working [5]; and
- engage with all key stakeholders [3]

In particular, Benton's B*Psy*© model of organisational effectiveness [6], clearly identifies the stages required to align the behavioural preferences (examine assumptions/misperceptions) of individuals towards effective team working (upgrade sharing of information/views), encouraging constructive controversy (resolution based mutual respect), and principled decision making towards synergy of values (potential autonomy) and views, as seen in Figure 1.

Against this background, and in the context of ongoing tensions within NHS hospital Trusts [7], the study explored principal drivers of behaviour for doctors and managers in NHS Hospital Trusts in the early 21st century. Through:

- summarising the key findings from previous studies [7][8][9][10][11][12][13][14].
- exploration of the broader context within which NHS hospitals operate and
- via application of reputable models of organisational success [3][6],

the study sought to address a question at the heart of many NHS hospital Trusts. Namely:

> *Is there scope to achieve alignment of the aspirations of doctors and managers to the benefit of the broader organisation, and hence, to the positive benefit of patients?*

## 2. Methodology

A literature review approach was selected on the basis of availability of previous literature and research undertaken by academic institutions, eg [8] [12]; professional medical bodies, eg [9][11] and management institutions, eg [13]. No previous studies were found that had specifically set out to determine the potential for alignment of aspirations, although significant bodies of evidence relating to the subject of 'drivers' and 'motivations' existed, albeit predominantly relating to either (rather than both), occupational group.

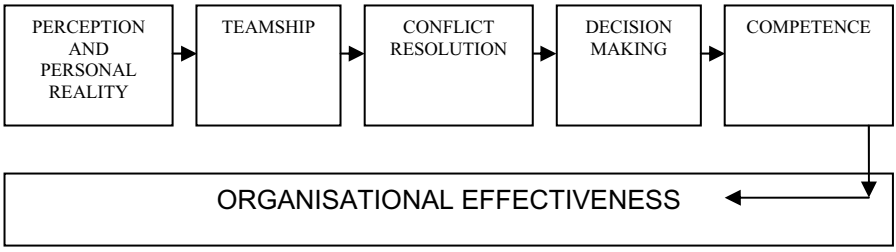


Figure 1: THE CONTRIBUTION OF BUSINESS PSYCHOLOGY TO ORGANISATIONAL SUCCESS

For the purpose of the study, the word 'aspiration' was defined solely in relation to professional drivers for including: Goals, Core Values, Professional Codes of Behaviour, Needs and Sources of Frustration

## 3. Key Findings

A medical consultant, who shall remain anonymous, shared a story which he confirmed accords with his own experience of managers in the NHS:

*A bright red new sports car stops at the top of a hill and its occupant jumps out to greet a shepherd and his flock. The car driver says "If I can guess how many sheep you have, would you give me one of them?"*

*"OK" said the shepherd.*

*After consulting with an array of electronic gadgets, the driver says "967".*

*"Well done" said the shepherd, "You can choose one of my sheep, but if I can guess your profession, can I have it back.*

*"OK" says the driver.*

*"You are an NHS Manager" says the shepherd",*

*"I'm amazed" said the driver, "how did you know that?"*

*"Easy – You arrive without being invited, consult with technology to tell me something I already know, and you clearly understand nothing about my work. Now can I have my dog back?"*

Whilst clearly intended in good humour, the story would undoubtedly strike a chord with many hospital doctors and managers in the NHS in 2006. In all likelihood, similar stories conceived by managers, and referencing the attitudes of hospital doctors are probably also in circulation within NHS circles.

Analysis and synthesis of the available literature provided the following insights into each aspect of the aspirations definition.

## 4. Goals

According to Furnham [5], conflict occurs when:

*"Mutually exclusive goals (or values) exist, or are perceived to exist by the groups involved"*

Evidence from the literature supports the potential for conflict to some extent. Doctors, for example are very clearly driven by a desire to gain peer recognition and to be respected. Managers do not appear to be similarly driven.

Striking similarities were found in the strength of feeling articulated by both doctors and managers in respect of achieving autonomy, and influencing change. Discreet differences however were hidden within these similarities. For example, the doctors' desire to achieve professional autonomy is underpinned by an understanding amongst doctors that autonomy is 'earned' [15]. This links to the traditional ethos of doctors learning their 'trade' through apprenticeship, and gradually earning a right to make autonomous decisions about patient care [16]. Conversely, managers' desire for autonomy is linked more to feeling empowered to innovate and take risks, whilst

pursuing achievement of organisational targets or objectives as dictated by central Government [10].

An area where doctors and managers appear aligned is that of needing to be allowed to influence changes that affect them, or their organisations. Exploration of the Department of Health Web site at www.dh.gov.uk [17] and of documents relating to NHS history [18] provides evidence of the extent of change in NHS hospitals in recent years. In reality, doctors and managers recognise that they are functioning within organisations with flawed systems, processes and infrastructure. Both are frustrated that the relentless challenge towards attainment of targets takes precedent over a genuine desire to improve the system, to the benefit of patients. Dr Ian Bogle, then Chairman of the British Medical Association Council, said:

> *"Doctors are finding they have not got sufficient time for patients. Expectations are very high, and the Government are putting in what we think are unreal targets that are causing great frustration within the medical profession" [19]*

Whilst there is a likelihood of shared interest regarding improving systems and organisational infrastructure, conflict occurs where doctors perceive managers as simply acting as servants to a Government; rolling out initiative after initiative without due care or attention. In reality, evidence shows that managers feel as uncomfortable about this as doctors [20]

Professor Rajan Madhok summarised this view when delivering the Milroy Lecture at the Royal College of Physicians in 2003 [21]. He said:

> *"Sometimes I feel that doctors and managers are so busy fighting each other across the chasm rather than joining forces to overcome the other elements that are also slowing down progress in the NHS"*

## 5. Core Values

Potential for conflict between doctors and managers is illustrated by many references to doctors being trained in a culture of individualism [7]. This can be both a help and a hindrance to doctors; helpful in that it encourages doctors to develop a sense of responsibility towards individual patients. A hindrance in that doctors often report feeling 'alone' and unsupported by colleagues [11]. Managers, on the other hand, are schooled within an ethos of collectivism in terms of shared accountability for organisational outcomes [22].

The culture of individualism extends to doctors operating from a value system driven by an understanding of *individual* accountability. This, undoubtedly, links to the desire for autonomy, on the basis that if doctors are to be held to account for the outcome of an individual patient, it follows that he/she must be allowed to decide on the best course of action for that patient. It seems likely that this aspect of autonomy may also link to doctors reporting feeling 'alone' in their decision-making. This value system makes doctors quite resentful of systems that operate on the basis of a clear and transparent process, policy and procedure, ie those systems within which managers can operate quite comfortably. These counter cultures may help explain why doctors might perceive insistent policy as dogma and an over interference, by managers, of clinical practice [15]; particularly where the Government have introduced formal structures for measuring the quality of clinical outputs via the National Institute for Clinical

Excellence (NICE), or the Commission for Health Improvement (CHI) [23]. Managers, as part of their role, are under obligation to report compliance with such standards and can, therefore, be resented by doctors for doing so.

Another source of potential conflict is linked to doctors exhibiting institutional loyalty to a single hospital, and managers moving from organisations more frequently, as opportunities for development and utilisation of their more 'general' skills arise [13].

Doctors might interpret management changes to be both disloyal to organisations, and to be a factor contributing to institutional instability. In particular, with so many Government initiatives forthcoming, there will be an insecurity linked to the fact that managers are often not around to see an initiative through. Inevitably, it will be a factor that contributes to a perception of NHS 'management', in itself, being a negative and unnecessary concept.

## 6. Codes of acceptable behaviour

What is apparent through an analysis of the similarities and differences between the doctors' and managers' 'codes' [24] [22], is that the emphasis for doctors is related to treatment, and responsibility for individual patients, and for managers, to the team, organisation and community. This concurs with the core values identified above.

In terms of similarity, both doctors and managers are expected to make patients their 'first concern'. Evidence shows that both groups also cite this as high priority in terms of their own goals. It is interesting, therefore, that doctors often perceive that managers do not care about patients [23]. Managers might argue (albeit in private) that the imposition of numerous targets can get in the way of a desire to keep patients as a prime focus [20]. Therefore, as a direct result of managers holding to a 'corporate' line in respect of target attainment, damaging misalignment of perception increased tension, and conflict, can occur between two parties who are, in actuality, driven by the same intent.

A further similarity links doctors and managers by mutual regard for trust, honesty and integrity.

Interestingly, doctors express concerns regarding managers being required to 'manipulate' data to attain targets [14]. They report this activity as being a challenge to their integrity. In reality, doctors may possess no evidence of data manipulation, but might be assuming manipulation through lack of understanding of complex data reporting systems. This is therefore likely to be linked to doctors concerns over the manner that control is exercised over broader organisational functions, or indeed, a Government agenda, that demands scrutiny of the quality of their individual clinical performance (23].

## 7. Needs

McClelland [25] suggested that individuals work to fulfil internal needs. He proposed three needs categories; achievement, affiliation and power and suggested that individuals will have one need type that is stronger than the other two. Applying McClelland's theory to the findings from the studies analysed indicates that doctors possess a strong need for affiliation, (manifesting itself in a need for peer recognition and support from colleagues) whilst NHS managers exhibit a stronger need for

achievement (illustrated by a need to attain targets and meet organisational objectives). Interestingly, neither group exhibited a strong *need for power*; a trait, perhaps more prevalent in organisations where individuals aspire to lead as well as manage. Weaknesses in leadership within the NHS are well documented [8]; a fact that has been proven to reduce the effectiveness of NHS organisations [26] and, perhaps, lead to frustration and conflict between those seeking affiliation, and those seeking achievement, in the absence of any powerful force providing leadership that could unite the strengths of individuals towards a achieving a positive vision.

Both doctors and managers reported needing clear, attainable targets. Interestingly doctors do not appear to be against targets, per se. However, they expressed a need to be involved in determining what those targets should be before they could commit to being engaged in their delivery. In reality, this engagement is rarely present, not least because the directives from national Government level are constantly changing. This leaves local managers and doctors in a position where, by necessity, they are re-active to changing emphases, rather than in a position to pro-actively plan for them. A senior manager interviewed as part of the Luck, Legacy or Leadership study [8]) said:

> *"We have hit all that activity and financial targets and achieving Foundation Status. Everyone is upbeat but there is a feeling of doing better but feeling worse"*

Prevalent throughout the literature were doctors making reference to the necessity for achieving an appropriate level of work/life balance. Managers made some reference to the same subject, but not as frequently. From a doctors perspective there were links made to a traditional *understanding* that doctors would 'earn' a better work life balance as their careers progressed towards consultant level [7]. Interestingly, over 90% of participants in the BMA cohort study [9] report a desire to progress towards consultant level within their careers. Conversely, for those deciding to leave the profession [11], all make some reference to the link between work life balance and their decision to leave the profession. For some of these, they have clearly had bad experiences with a lack of support from colleagues in this area. One doctor interviewed as part of the BMA cohort Study [9] said that a colleague made negative reference to *'hobby doctors'*. Another cited a perception that *'patients make you feel guilty'.*

Whilst doctors are increasingly citing work life balance as a need, managers are more likely than doctors to articulate a need for a clear vision and objectives. This may relate to the fact that managers are driven more by a need to influence the success of the organisation as a whole, and thus need clarity regarding the direction of travel towards a defined vision [3].

## 8. Sources of frustration

Sources common to both groups engendered frustration. Of most significance were the similar responses relating to issues concerning; too much bureaucracy, too many initiatives, and not being listened to / changes being imposed. It is important to highlight the fact that whilst it would be reasonable to assume that doctors would attribute excessive bureaucracy and change to their management colleagues, in fact their frustration is more targeted towards central Government than to the managers with whom they work at local level. Evidence for this was provided by analysis of the 175 motions presented to the 2006 Conference of Representatives of Senior Hospital

Medical Staff [27] Over 80% of these made reference to dissatisfaction with Government initiatives while none made negative reference to local management, and indeed, some specifically made positive reference, as follows:

*"Crises in the NHS are created by the Government and not local management"*

It is interesting, and somewhat unexpected, that NHS managers, as well as doctors, express frustration related to imposition of change, and initiative overload. Indeed, it was a manager who, as part of the Optimising Value [13], said:

*"Target setters need to re connect with the front line, and listen to those providing the services"*

In all relevant studies analysed [7][8][9][10][11][12][13][14], doctors cited a lack of support as being a source of frustration. This related predominantly to support from colleagues from within the same profession. Worryingly, it featured strongly in individuals' decisions to leave the profession and was summed up by one member of the BMA cohort study [9] as:

*"The support wasn't really there. It was fake. Senior doctors treated you badly because they knew you knew nothing, and yet would not teach you properly because they were too busy."*
(Dr M, Female)

Once again, the subject of erosion of professional autonomy featured significantly in relation to doctors' frustrations. An example of this can be found in a study by Edwards [7], where those interviewed made reference to an uncomfortable shift in the psychological paradigm between doctors and society. Relating this expectation to *equity theory* of motivation [28], it could be suggested that tension will have arisen as doctors have observed the evolution of imbalance between what they offer, and what they receive in return. From a doctor's perspective, they have continued to fulfil the duties previously expected of their profession, but that which they could previously have expected in return is not forthcoming. The shortfall on return to be found in those structural and interpersonal supports based upon recognition of their role as the arbiter of best practice within the organisation.

Whilst the evidence would suggest that doctors do not attribute the cause of their frustration to 'local' managers, clearly day-to-day tensions, at a local level, do still occur. One reason for this may be that managers are now perceived as the arbiters' government led rules and targets to which the organisation as a whole, must respond.

## 9. The Broader Context

In researching the potential for aligning aspirations, it became clear that many barriers could be traced back to frustrations with the broader national NHS agenda, rather than to specific differences in aspiration between individual doctors, and individual, local managers. However, there are, of course, a number of differences in the pressures that drive and shape the approaches taken by doctors and managers.

Of more significance, is the manifestation of frustrations caused by a perception of change being imposed from a national level. Professor Frank Blackler, author of Chief Executives and the Modernization of the English National Health Services [20], kindly offered an insight during research for this project. He said:

> *"I think medics' antipathy towards NHS managers in particular dates back to the Griffiths report, and was later exacerbated by the Tory reforms and their efforts to introduce what academics came to call "the new public management. This was probably the origin of the contemporary attack on the degrees of freedoms medics have enjoyed"*

Interestingly, the Griffiths report [1] clearly refers to the necessity to involve clinicians more closely in the management process. Whilst this statement, alone, could be construed to imply that doctors would continue to enjoy high levels of authority within the NHS, the report, in section 19, also states that

> *".. as doctors decisions largely dictate the use of resources they should accept the management responsibility which goes with clinical freedom"*

Manfred Davidmann, in his Evaluation of the Griffiths Report [29], interpreted this aspect of the report to imply that, in future, doctors would be required to adhere to decisions made by managers. Davidmann's predictions in this regard were well founded, and persist to this day. Reference to this perception is clear in the views articulated by doctors regarding their assumption that decisions imposed [14].

Another area of significant concern, from the perspective of doctors and managers is the 'over politicisation' of the NHS, coupled with intense media scrutiny, and public expectations. Health care and the NHS attract high levels of media coverage, which has served to intensify the sense of political and public scrutiny. While doctors strive to achieve best medical care within a framework designed to deliver on targets set to a minimum national standard, they are fully aware of the capacity of media coverage highlight individual cases. It appears that the healthcare arena is large and one currently dominated by a view of health as an amalgam formed by issues of organisational change and management and the political agenda. In the UK is has become normal to; open a newspaper, turn on the television news and find another story about the financial crisis in the NHS, or an individual patient who has been required to wait a long time for treatment. In most cases there will be some reference made to poor management within individual NHS institutions. Government representatives will also appear, or be quoted, making reference to the high levels of investment made in the NHS, and the mis management of resources. Meanwhile, within individual hospitals, doctors, managers and other professional and support colleagues will be continuing to work hard, within complex organisational structures. All will be driven by a public sector ethos, and with a desire to provide high standards of care. Inevitably, each article or news story that appears will adversely affect morale; leading to a context where individuals might look for others to blame. For doctors, it is easy to blame 'the system', and to see local managers are representatives of that system. In the tenth annual report of the BMA longitudinal study of 545 doctors [30], a doctor said:

> *"The problem is the system we have to work in, ridiculous levels of bureaucracy and paperwork, rules for the sake of rules and political correctness gone made"*

For managers, it is easy to blame the individualist approach of the doctor, seeing doctors as blocks to organisational success.

In summary, whilst individual hospitals possess a degree of autonomy in relation to planning and decision making, in reality, the level of this is less than envisaged by Griffiths [1] when he suggested that most decisions would take place 'within individual hospital units'.

## 10. The potential for organisational effectiveness: Towards Re alignment

Dean Tjosvold [3] created a model of organisational effectiveness, arguing that the conditions for all five factors (Envision, Unite, Empower, Explore, Reflect) needed to be present within an organisation if it was to achieve, and sustain, success in this context to achieve high quality patient-centred care. By overlaying the key findings from the literature onto Tjosvold's model, it is clear that the conditions currently reported by doctors and managers are, to a significant degree, misaligned and not conducive to organisational success and, hence, in the best interest of patients. Whilst this gives cause for concern, it is important to consider, conversely, the shared interests that were clearly expressed through previous studies by doctors and managers. In summary:

**Table 1** Doctors and Managers: Potential Alignment

| | |
|---|---|
| Envision: | Both codes of behaviour place patients at the forefront of practice |
| Unite: | Both report needing to work towards clear, attainable targets |
| Empower: | Both report needing to be listened to |
| Explore: | Both report a desired goal to influence change |
| Reflect : | Both report a need for time out to reflect |

Whilst doctors and managers work within a fast moving and stressful environment, there is sufficient autonomy at local level within NHS hospitals to develop structures that support the Tjosvold model. Importantly doctors and managers must acknowledge that they share a frustration regarding targets and initiatives imposed upon them from national level. Left unarticulated, these frustrations can and do generate behaviours that act as blocks undermining opportunities in areas of practice over which doctors and managers can exercise local control and influence. This initial and fundamental misalignment between these two key professions undermines an organisation's ability deliver on its core objective and 'put the patient first' as doctors' medical priorities can conflict with managers tactical and forward looking resource strategies, leading to organisational failure. The Bp*sy*© model identifies five elements necessary for the achievement of organisational effectiveness based upon the recognition and resolution of those interpersonal misalignments that undermine, in this case, both groups' opportunities to re assert commonly held objectives for patient care. This potential is expressed in Figure 2.

### *10.1. Perception and personal reality*

Evidence showed that doctors and managers share a public service and care ethos aligned with a commitment to provide the best service for patients. Not withstanding the common concern for the integrity of care that each individual patient should expect, it seems that these shared, patient centred, interests can be obscured by the antagonistic perceptions which then interfere and undermine the pursuit of common ground.

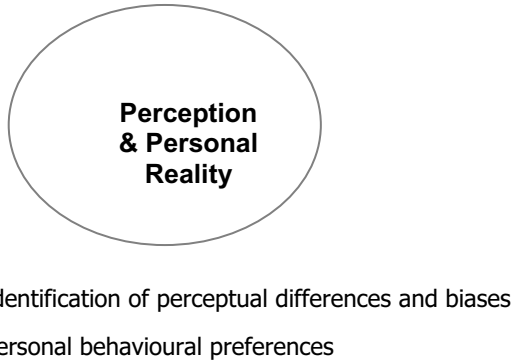


**Figure 2**

In particular, doctors can see managers as the manifestations of those that set unattainable targets while managers can perceive doctors to be arrogant, and disinterested in organisational success. Within this volatile mix of perceptions the influence of communication and behavioural styles may further polarise expressed views, emotions and positions. Yet, ultimately, it is this environment that forms the local context within which the large-scale issues of resources, targets and quality of medical care are addressed and scaled down to deliver day-to-day quality of care for the patient.

It is arguable that improvements in the quality of interpersonal transactions, within this local context, could support better; team climate, resolutions and better quality of information exchanged thereby promoting creative and unified team actions on delivery of primary aims. Differences in each group's professional training and hence preparation for working within such, power-sharing teams may also distort transactions.

### *10.2. Teamship*

Evidence showed clear differences in the training and development culture of doctors and managers. Managers were routinely required to work within and to lead teams, without which the link between their strategic and tactical deliveries would not be possible. The front line and time-critical problem solving, characteristic of medical practice, encourages robust and independent decision making. It is possible that in order to deliver on task, that these two professions acquire different, if not polar-opposite, approaches and skill sets which, when brought together into the team

environment, prompt misperception and misunderstanding. Teams are a fundamental part of an organisations' capacity to deliver primary objectives, if senior teams are

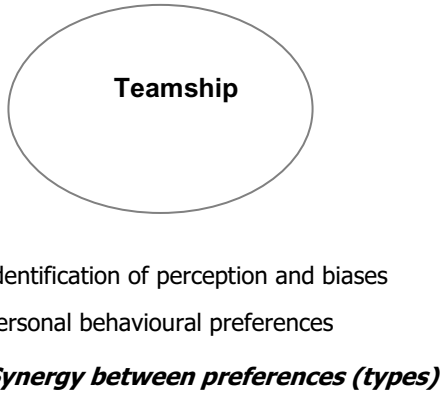


**Figure 3**

failing to build effective understanding and jointly agreed outcomes then primary objectives may suffer from delayed decisions, inappropriate holding measures and postponed planned development. Given the complexity and depth of tacit influences acting to shape miscommunication, it is suggested that improved team performance could be directed through an explicit team structure, one that guides the interaction and impact of type differences through a series of interactive team processes. If managers were encouraged and able to explore and understand the individualist perspective from which doctors operate, and, conversely, if doctors were encouraged to explore the concepts and processes of a collectivist approach, this could lead to enhanced mutual understanding of each others needs, and hence, enhanced cross disciplinary team working. Promoting these team methods would assist in clarifying the sources of friction, however clarification would also highlight the need for improved resolution.

*10.3. Conflict Resolution*

Patient care is intimately linked with the capacity of the hospital team to move through position based differences, with attendant time delay and preference based distortion of issues, to create ways to identify overriding issues and to develop effective actions. Without full conflict exploration and resolution subsequent actions can lack commitment to follow through and lead to sabotage through avoidance. The evidence from the study, suggests that doctors and managers have traditionally encountered each other's views as a mismatch of the principled and the expedient. Without the preceding elements of team building it is unlikely that such teams would be able to reach outcomes based upon pursuit of the widest range of perspectives. To do so would run the risk of simply generating; further options for conflict and associated failed resolution, further damaging relationships and undermining hard won compromises endorsed by agreement. If doctors and managers were encouraged and equipped to work through preference-based biases, within a structured team process (Figures 2 and 3), there arises the possibility of utilising preferences as problem solving aids to

operate within a resolution model, derived from the 'principled' approach [31][4]. See Figure 4.

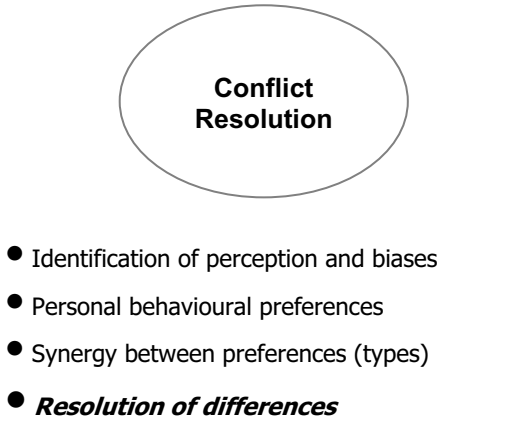


**Figure 4**

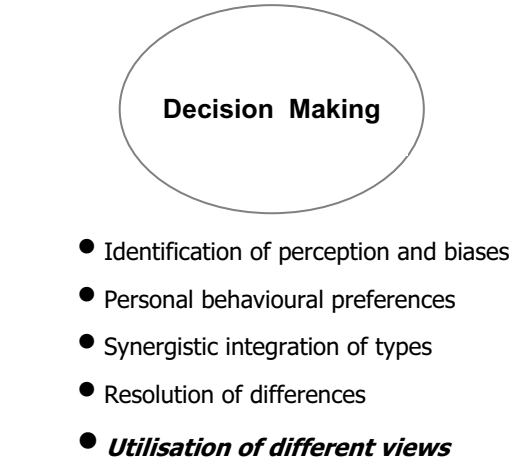


**Figure 5**

*10.4. Decision making*

Decisions made by the team represent the point at which strategy emerges as action, with direct consequences, in this case, for the patient. Whilst the evidence showed that both doctors and managers shared a frustration regarding the imposition of national initiatives and priorities, there is little evidence that the two groups freely discuss this mutual frustration.

Decision-making can only be as good as the quality of available information and analyses permit, and the evidence from the study suggests that the information transacted between the groups is biased and organised around polarised positions. The origin of such differences in positions has been examined in the preceding sections, each of which highlight the pressures likely to inhibit decision making quality, particularly as issues of, resources, priorities and national targets comprise elements of a forced-choice nature. The evaluation of such options and targets will require a capacity to retain the quality of information shared even through periods of conflict, when information is likely to distort and to prompt a reversion to costly polarised positions. The need to support relationship communications is an integral part of effective team decision-making as both groups would be dependent upon the other's willingness to share information and work towards building fresh alternatives that clarify decisions to be made, through making use of different viewpoints. See Figure 5.

Freedom of articulation in a safe environment would enable issues to be acknowledged and where feasible, placed aside leaving doctors and managers free to make decisions about areas of operation over which they have local control. Rather than doctors continuing to perceive management to make decisions that affect them, they would be involved in the decision and hence engaged with the process of implementation.

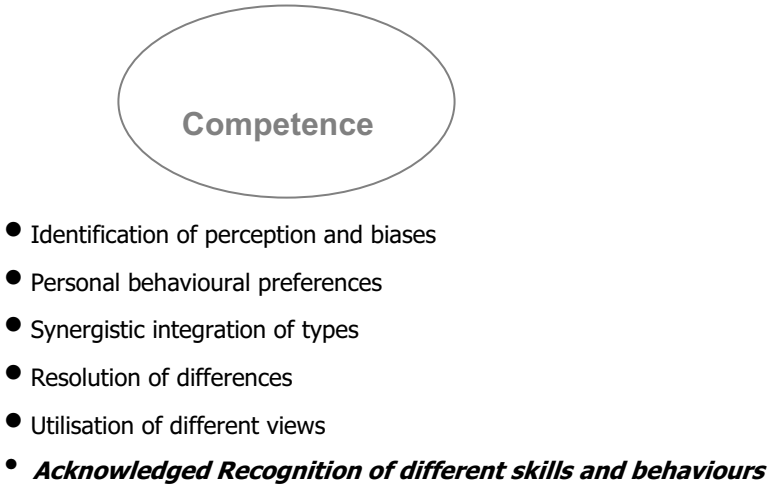


**Figure 6**

*10.5. Competence*

Figure 7 illustrates the manner in which each of the preceding elements combines to form a coherent In the Benton B*psy* model [6] successful application of steps within Figures 2 to 5 contribute to team competence (Figure 6), and to organisational success. Whilst activities proposed above would represent a significant shift in culture within hospitals, demanding, for example, far greater integration between doctors and managers, it is considered feasible that these steps are within the control of individual

hospitals. Success, would, of course, be subject to strong, credible, and inspirational leadership, and to a sustained commitment to the achievement of full mutual engagement [32].

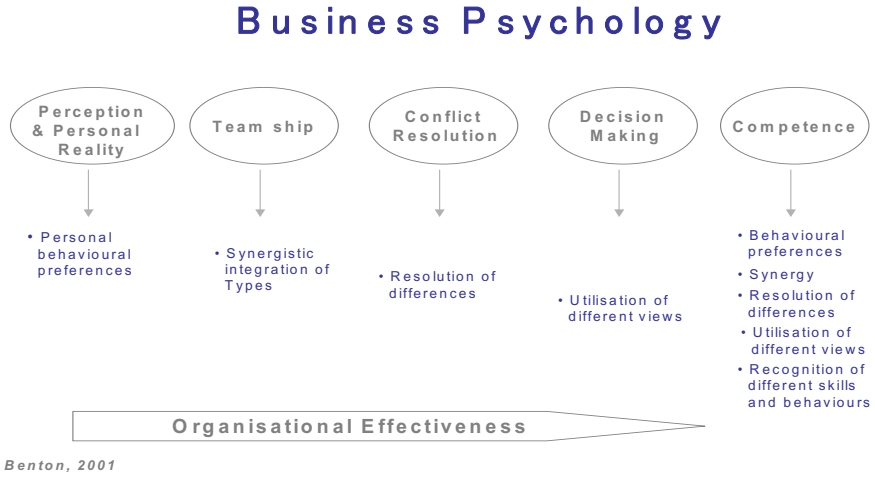


**Figure 7**. The Business Psychology Model (B*psy*): An integrated approach to utilising the fundamental behavioural component of individual preference as a means to improve performance in each of the core modules. [6][33]

## 11. Conclusion

Dr Catherine Bailey, co director for the Cranfield Management School's 'Luck, Legacy or Leadership' project [8], was asked to provide her personal response to the research question. She said:

> *"I believe that difficult as the NHS context is, the issues of aspirational alignment are fundamentally problematic in most organisations, and for most boards in the private sector too, (particularly those facing high velocity, turbulent change (most!) ). So does the NHS and acute Trust executive setting present a context (ie legacy, structure, culture, policy, strategy etc) that simply renders alignment literally impossible? – Personally, I think not. It is certainly difficult for a diverse array of deep rooted reasons, but it is not impossible."*

Synthesis of material from previous studies [7][8][9][10][11][12][13][14] is in accord with Dr Bailey's view. Indeed, clear evidence was found of the potential for alignment, on the basis that a range of shared interests and, indeed, shared frustrations, between doctors and managers have been discovered. However, the potential for alignment is often blocked by the presence of history creating cognitive bias; assumption of differing agenda and intent; position holding behaviours, and lack of belief regarding the potential for allowing degrees of responsible autonomy within organisational constructs.

## References


[1] Griffiths R (1983) NHS Management Inquiry Report London: HMSO.
[2] Mullins L J (2005) Management and Organisational Behaviour. 7th Ed. Harlow: Pearson Education Ltd.
[3] Tjosvold, D (1992) Team Organisation: An Enduring Competitive Advantage. Chichester: Wiley.
[4] Ury, W (1991). Getting Past No: Negotiating with difficult people London: Business Books Ltd.
[5] Furnham A (2005) The Psychology of Behaviour at Work: The Individual and the Organisation . Hove: Psychology Press.
[6] Benton, S (2001) BPsy Model of Organisational Effectiveness: A Snapshot: BPC technical paper.. Business Psychology Centre, University of Westminster, 2001.
[7] Edwards N (2001) The Problem of Unhappy Doctors – What are the causes and what can be done London: NHS Confederation.
[8] Bailey Dr C and Burr J (2005) Luck, Legacy or Leadership: The Contribution of leadership to sustained organisational success in NHS Trusts: Interim Report June 2005 Cranfield School of Management: Beds.
[9] British Medical Association – no author cited (2004) Longitudinal Cohort Study of 545 '1995 graduates', Ninth Report London: BMA Health Policy and Economic Research Unit.
[10] Charlesworth K, Cook P, Crozier Dr G (2003) Chartered Management Institute: Leading change in the public sector – Making a Difference: London: CMI.
[11] Cooke L and Chitty A (2004) Why do Doctors Leave the Profession ? London: British Medical Association.
[12] Finlayson B (2002) Counting the Smiles – Morale and Motivation in the NHS London: Kings Fund.
[13] Graham A and Steele J (2001) Optimising Value – The motivation of managers and doctors in the NHS London: Public Management Foundation.
[14] NHS Confederation – no author cited (2003) Medicine and Management – Improving Relations between Doctors and Managers London: NHS Confederation.
[15] Harrison S (2003) Medical Autonomy and Managerial Authority in the National Health Service: Institute for Political and Economic Governance: University of Manchester.
[16] Mimnagh CJ, Murphy M (2004) Junior Doctors Working Patterns: Application of Knowledge Management Theory to Junior Doctors' Training: St Helens: St Helens and Knowsley Health Informatics Service.
[17] Core NHS Standards document. Copy of National Standards, Local Action: Health and Social Care Standards and Planning Framework 2005/2006, 2006/2007. Also references to NICE and CHI Available: www.dh.gov.uk.
[18] Collini E, Grant K, Greengross P (1999) The History and Development of the National Health Service 1948 – 1999. 2nd Ed. London: Health Systems Resources Centre Publications.
[19] Interview with Dr Ian Bogle – Then Chairman of the BMA Council A press release following interview between Dr Bogle and the BBC, on the eve of the BMA Conference, in Bournemouth, in 2001.
Available: www.news.bbc.co.uk/1/hi/in_depth/health/2001/bma_conference
[20] Blackler F (2006) Chief Executives and the Modernization of the National Health Service, in Leadership Vol 2(1): 5-30: London: Sage Publications.
[21] Madhok R (2003) Doctors in the new millennium: Hippocrates or Hypocrites? Milroy Lecture, delivered at the Royal College of Physicians: London 16th September 2003.
[22] Jarrold et al (2002) Code of Conduct for NHS Managers. London: Department of Health Publications.
[23] Charlton B (2000) The new management of scientific knowledge: A change in direction with profound implications, in NICE, CHI and the NHS Reforms: Enabling Excellence or imposing control? London: Aesculapius Medical Press.
[24] General Medical Council (2001) – no author cited Good Medical Practice London: General Medical Council.
[25] McClelland (1985) cited in Hodson C (2001) Psychology and Work Hove: Routledge.
[26] Borrill Dr C, Dawson JF, West Prof MA (2004) The Relationship between Leadership and Trust Performance Birmingham: Aston Business School.
[27] Motions of the Conference of Representatives of Senior Hospital Medical Staff (2006) A copy of the conference agenda, held on 7th June 2006, at The Mermaid Conference and Events Centre, Puddle Dock, Blackfriars, London EC4V 3DB
Available: www.bma.org.uk/pdfConferenceAgenda.
[28] Adams (1979) cited in Mullins L J (2005) Management and Organisational Behaviour. 7th Ed. Harlow: Pearson Education Ltd.

[29] Davidmann M (1984) Reorganising the National Health Service: An evaluation of the Griffiths Report . ISBN 085192 0462.
[30] British Medical Association – no author cited (2005) Longitudinal Cohort Study of 545 '1995 graduates', Tenth Report London: BMA Health Policy and Economic Research Unit.
[31] Fisher R,. Ury, W and Patton, B (1997) Getting to Yes: Negotiating an agreement without giving in. Arrow Punlciations Ltd.
[32] Borrill Dr C, Dawson JF, West Prof MA (2004) The Relationship between Leadership People Management, Staff Satisfaction and Intentions to Leave Birmingham: Aston Business School.
[33] Benton, S. (2005) Each Individual is the exception to the Rule. APM Yearbook, 2005/06. pp.32-36.

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# The Transition from 'Informed Patient' Care to 'Patient Informed' Care

Ruth GARDINER
*Managing Director*
*HealthSystems Consultants Ltd*

**Abstract** We are in the midst of a real change in the application of information technology to support the delivery of healthcare. We are seeing a shift from the 'informed patient' which has resulted from improved access to healthcare information, primarily from the Web, to the 'participative patient' as we move into Web 2.0 territory.

The last decade has seen significant strides in the application of healthcare information to support patient care including:

- Increased access to healthcare related information by the patient through access to healthcare information on the Web (1.0).
- The development of electronic patient/health records.
- Improved access to knowledge for care professionals has enabled the dissipation of professional clinical skills with the introduction of nurse practioners and increased use of therapies.
- Improved access to patient related information across disciplines is beginning to enable the shift from acute based to community based care.
- The introduction of home care technologies has enabled self monitoring in supporting self care.
- There are also developments in the way care is provided with an increasing diversity of healthcare providers with the challenges this has presented in exchanging patient related information to support continuity of care.

We are now at another major turning point that could present greater challenges for healthcare professionals, organisations and the patient or client. These developments include:

- The application of information sharing services commonly referred to as Web 2.0. As a result we are seeing a transition from the 'informed patient' to the 'participative patient' that will present increasing challenges for healthcare professionals and healthcare organisations in adapting care to embrace this evolution.
- New entrants to the ehealth market are now emerging such as Google and Microsoft who are competing to 'own' the 'healthcare consumer'.
- Open source solutions for EPR/EHRs are now emerging that will challenge the traditional mechanisms for delivery of organisational healthcare solutions.
- Technologies that have been growing in use and demand over the past decade are now being applied to healthcare including digital TV and mobile computing.

What then are the challenges for patients, healthcare organisations and information service providers as we move from the passive role of the patient in the provision of their care to a more participative role?

## 1. Introduction

We are in the midst of a real change in the application of information technology to support the delivery of healthcare. We are seeing a shift from the 'informed patient' which has resulted from improved access to healthcare information, primarily from the Web, to the 'participative patient' as we move into Web 2.0 territory.

The last decade has seen significant strides in the application of healthcare information to support patient care including:

- Increased access to healthcare related information by the patient through access to healthcare information on the Web.
- The development of electronic patient/health records.
- Improved access to knowledge for care professionals has enabled the extension of clinical skills across professional boundaries with the introduction of nurse practioners and increased use of therapies.
- Improved access to patient related information across disciplines is beginning to enable the shift from acute based to community based care.
- There are also developments happening in the way care is provided with an increasing diversity of healthcare providers which has brought new challenges in how patient information is exchanged between organisations to support continuity of care.

We are now at another major turning point that could present greater challenges for healthcare professionals, organisations and the service user or consumer, be they patient, client or carer. These developments include:

- The application of information sharing services commonly referred to as Web 2.0. As a result we are seeing a transition from the 'informed patient' to the 'participative patient' that will present increasing challenges for healthcare professionals and healthcare organisations in adapting care to embrace this evolution.
- New entrants to the ehealth market are now emerging such as Google and Microsoft who are competing to 'own' the 'healthcare consumer'.
- Open source solutions for EPR/EHRs, (Electronic Patient Records, Electronic Health Records), are now emerging that will challenge the traditional mechanisms for delivery of organisational healthcare solutions.
- Technologies that have been growing in use and demand over the past decade are now being applied to healthcare including digital TV and mobile computing.
- The introduction of home care technologies is starting to enable self monitoring to support increased self care, particularly for chronic diseases.

What then are the challenges for healthcare consumers, healthcare organisations and information service providers as we move from the passive role of the 'patient' in the provision of their care to a more participative role?

## 2. The 'Informed Healthcare Consumer'

### *2.1. Developments in Healthcare Information*

First of all we need to set some of the context for this transition and the challenges it will present by taking a brief look at how the delivery of healthcare has developed over the past decade.

Most major healthcare systems have undergone significant changes in the way care is delivered in recent years. The United States have been developing the concept of managed care for a number of years with the ability of US patients to choose their care providers, forcing a need for their information to be transferable, hence the HIPAA, (Health Insurance Portability and Accountability Act of 1996), legislation. Now across Europe the structure and organisation of healthcare systems is changing to encompass similar concepts. Reforms to European healthcare systems have introduced a distinctive European form of managed healthcare which starts from a premise that health is a social responsibility. The state and the community are therefore involved in directing and setting goals for health and healthcare.

In the UK from the early nineties market forces have been introduced to create competition within healthcare provision with a view to increasing quality and forcing costs down. Until recently competition was largely confined to NHS providers however the latest developments within the UK have seen large scale contracts awarded to independent sector providers to provide NHS services for elective, diagnostic and latterly primary care services. The UK however has remained a highly directed market with public and quasi public institutions ensuring that health services meet goals of equity and affordability.

The traditional roles within the context of healthcare provision have also changed. In the past the primary relationship has been between 'patient', as the recipient of care and medical, nursing and allied healthcare professionals as the primary 'providers of care'. Care provision has largely been contained within organisational boundaries with movement between these boundaries largely controlled by the GP, in the UK at least. This has now changed to a more diverse set of relationships with attempts to make the movement between organisational boundaries much more fluid. Health and social care services are aligned more closely than before which means the concept of a 'patient' is no longer an appropriate term to describe a consumer of care services.

Healthcare services also need to be seen in the context of supporting 'wellness' as well as 'illness'. Again the concept of a patient as the main consumer of 'healthcare services' is inappropriate. For the purposes of this discussion therefore the terms 'consumer' or 'person' and 'care professional' have been adopted to identify the key relationships and the term 'provider' and 'commissioner' used to denote the key organisational roles.

### *2.2. Information Developments within Healthcare*

The ability to manage healthcare effectively depends upon the proper use and application of information by consumer, provider and care professional. While pressures for healthcare reform may be seen as resulting from the ageing population, advances in medical technology and rising expectations, these factors have been apparent for at least the past twenty years. What has changed over the past decade has been the availability of better information with which to manage health status,

healthcare costs, the quality of healthcare services and moreover provide better access by the consumer to health related information.

Significant progress in development of information requirements is being achieved in the United States, Europe and Australasia, with a shift from an old world of narrow administrative systems towards a new world of managed healthcare systems. (See figure 1).

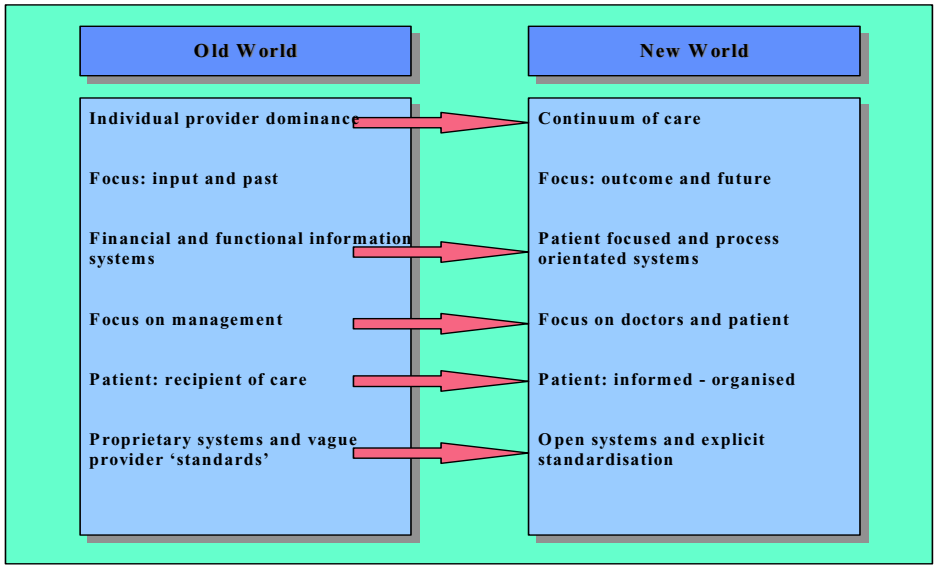



Figure 1 :The Change in Focus of Healthcare Information System Development [1]

The developments associated with electronic health records are intended to support the continuum of care across care settings to support care professionals in delivering a more joined up and holistic service to consumers and to avoid relying on the individual to retain and represent information about their condition, treatment and care for each intervention. Whereas in Europe and the US there have been significant strides in intra-organisation electronic 'patient' record systems whether this be within primary care or secondary care, inter-organisational information sharing has been more of a challenge.

In the US for example there have been developments around the concept of the RHIO (Regional Health Information Organization). This is a group of organizations with a business stake in improving the quality, safety and efficiency of healthcare delivery, facilitated through the concept of a Healthcare Information Exchange. This incorporates areas of technology, interoperability, standards utilization, harmonization, and business information systems to build a national network of interoperable health records. The concept of building a health information network requires extensive collaboration by a diverse set of stake holders.

In England the NPfIT (National Programme for IT), approach has been to build a highly centralised infrastructure based around the concept of each person having a national 'summary' record of all healthcare interventions held on the National Care Records Service 'Spine' populated from subsidiary systems held at local level but which have all been procured and are being implemented as part of the same Care Records Service Programme. Given the fact that such a mammoth programme can

never hope to be able to respond to the constantly changing environment that it is intended to support, it remains to be seen how well this approach will even meet yesterday's requirements let alone keep pace with new and emerging needs.

Other approaches to achieving electronic health records have been less ambitious in scale and have included the use of smart cards which puts the responsibility and ownership of a health record primarily with the individual rather than the organisation. All approaches however have the application of open systems, explicit standardisation and interoperability as critical pre-requisites.

Information and data exchange is critical to the delivery of quality care services and effectiveness of healthcare organizations. The benefits of appropriate sharing of health information among consumers, care professionals and other participants in the healthcare delivery value chain, are well understood and highly desirable. Few organizations and systems have taken advantage of the full potential of the current state of the art in computer science and health informatics as yet.

Improved access to healthcare related information has also been a key feature of the last decade which has had benefits for both consumers and care professionals alike but has presented challenges for both. For the consumer the ability to use the Web to access information on clinical conditions, treatments (traditional and alternative) and service providers has enabled people to become much more informed about their healthcare and the services available to them. This has presented challenges for care professionals particularly in having to respond to a much more informed patient. Easy access to electronic information in the form of guidelines, best practice and decision support systems has also supported moves to extend clinical practice across a broader group of professions with the introduction of nurse practioners and increased use of therapies as alternatives to purely medical or surgical care.

### *2.3. How 'Informed' is the Consumer ?*

Given the developments in healthcare and in healthcare information, how has the consumer been affected by the changes that have taken place over the last decade and are they really more informed?

Clearly access to publications and information on the Web has enabled the reasonably 'savvy' consumer to become more informed about their particular condition or the healthcare problems of their family members. In the UK on line services such as NHS24 and NHSDirect have been very successful in providing immediate access to advice which has reduced pressures on emergency and out of hours services and has provided consumers with a single recognised authority for immediate advice and guidance on health related matters, even for the less 'savvy'.

The increased plurality of healthcare provision has been a development designed to offer increased choice for consumers, as well as to promote competition and reduce cost. Choice has to be informed however to become a reality and currently, within the UK at least, the information that consumers require is sparse and in some cases not relevant to their decision making. Patient choices around secondary care provision is still largely influenced by the GP rather than a person's own assessment of options based on comparable information that is relevant to their decision making process.

The developments around electronic health records have not as yet provided any significant ability for the consumer to interact with their own health related information. The developments that are beginning to happen with provision of home based

monitoring tools that have the capability to link with care records provide evidence of how this is a key developing area assuming that care records solutions are in place to interact with.

The consumer can be said to be considerably better informed in terms of understanding their condition and the options for treatment but is still generally not a full participant in either the decision making process or the care process itself of how, when and by whom their care is provided.

## 3. Technologies to Support the Transition from 'Informed' to 'Participative'

### *3.1. New and Emerging Information Technologies within Healthcare*

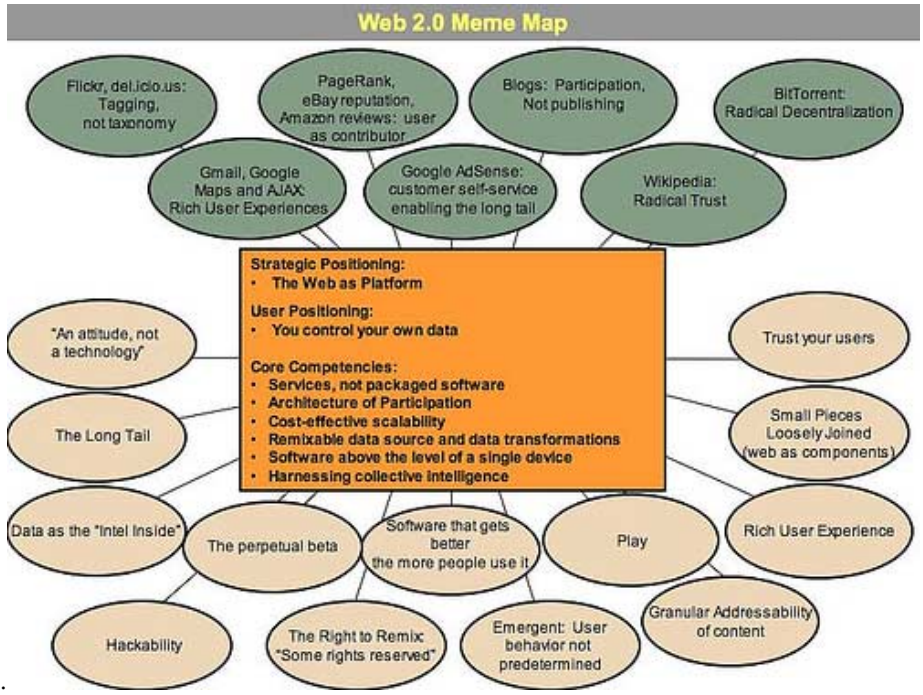
The more recent developments in access to information will start to see a real shift from both the consumer's perspective and the care provider's perspective from a purely passive but informed role to a much more active, participative role. The impact these developments will have on how care services are provided and the experience of consumers will depend on how these technologies are harnessed and directed to achieve greatest benefit.

We are now clearly at a major turning point in healthcare information development that could present the greatest opportunities and challenges for healthcare professionals, organisations and consumers. These developments include:

- The application of information sharing services commonly referred to as Web 2.0.
- Open source solutions for EPR/EHRs are now emerging that will challenge the traditional mechanisms for delivery of organisational healthcare solutions.
- Technologies that have been growing in use and demand over the past decade are now being applied to healthcare including digital TV, mobile computing and also healthcare specific devices that will enable greater self care.

### *3.2. The application of Web 2.0 within Healthcare*

Before we look at how Web 2.0 can apply to healthcare we first of all need to understand what is meant by Web 2.0. Received wisdom on the definition of Web 2.0 is that it is a bit of a catch-all which covers a broad range of new online services, user-generated content, communities and social networking tools. The phrase also refers to the creation of far greater levels of interactivity, not just between users, or between users and the internet but between complementary online services through mash-ups and web services. The most familiar names associated with Web 2.0 are Facebook, Blogger, Flickr, MySpace, YouTube and Wikipedia and clearly Google who have dominated access to the Web and have successfully migrated to Web 2.0. Figure 1 shows a "meme map" of Web 2.0 developed by Tim O'Reilly, CEO of O'Reilly Media which attempts to identify the characteristics of Web 2.0 [2].

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It would be a contradiction in terms to attempt to constrain the full potential of Web 2.0 in its application within healthcare to a number of key bullet points. However we can focus on three key features of Web 2.0 that clearly have the potential to resolve some of the real information challenges that are presented by healthcare. This includes:

- The natural evolution for the consumer from a passive role in accessing information to becoming more of a participant is in using Web 2.0 technologies to develop social networking communities for healthcare which are evolving towards becoming user-generated online medical portals.
- The application of Web 2.0 as a platform to support interoperation between organisations and with the consumer.
- Web 2.0 incorporates Services, as opposed to packaged software, with cost-effective scalability'. From a healthcare providers perspective 'Software as a Service' (SaaS) will provide access to applications online rather than having to 'buy' software.

### *3.2.1. Web 2.0 as the 'Architecture of Participation' within Healthcare.*

Web 2.0 has an implicit "architecture of participation", a built-in ethic of cooperation, in which the service acts primarily as an intelligent broker, connecting the edges to each other and harnessing the power of the users themselves [2]. Individuals increasingly have an expectation that their experience as a service user will be about reciprocity and mutual problem-solving, not the passive acceptance of a set of generic solutions and this is no different within the context of healthcare.

In England there are several examples of how web based technologies are encouraging a more participative role, albeit still relatively limited in being able to influence their own care proactively:

- Patient Opinion gives patients the ability to share experiences of their treatment with others. It acts as an independent intermediary to allow people to share their experiences of health care, and funnels the learning up from this anonymously to the services themselves to help the improvement process.
- My HealthSpace provides the patient interface to the English NHS Care Records Service. Early versions of the system give patients access to a web-based summary of their medical record, with future plans to add in full details of test results, medication history and information and knowledge resources. In its current form however My Healthspace is not interactive in that it cannot facilitate interaction with the care professional.
- NHS Choices is intended to provide consumers with information on the quality and responsiveness of particular NHS services and even individual clinicians.

Further afield examples of healthcare consumer participation using the Web includes:

- OrganizedWisdom, a firm based in New York launched in October 2006 as a type of health-care Wikipedia. The site allows consumers to add their own nuggets of health wisdom. After only a few months it has transformed itself into an index of the existing web content. The firm's founders had discovered that there already considerable user-generated health information online; the real problem was being able to sift it to find the relevant information.
- Health World Web helps ascertain the credibility of the physician chosen, by aggregating details of background information including education, training, board certification, disciplinary action(s), patient opinions and ratings and background checks.

It is already clear that the current application of Web and Web 2.0 content is beginning to enable greater participation. The use of sites like Patient Opinion and Health World Web will enable consumers to make more informed choices on the services which can be provided to meet their needs, providing information from other consumers, as well as the provider, that is meaningful to the consumer. The ability for consumer opinion to influence others will in turn force providers to focus on the quality of care and services they provide if they are to gain competitive advantage.

Collaboration between consumers enabled by the Web provides significant benefits for individuals in terms of mutual support. Individuals with specific conditions, particularly chronic conditions, such as diabetes, asthma and depression are able to get advice and support from others in similar situations. In some cases web-based information from other sufferers can augment or in some cases challenge medical opinion. The BrainTalk Communities is an online support group for neurology patients that has been going since 1993. In a BrainTalk study [3], 40% of respondents said they used the site because their doctors did not or could not answer their questions.

One of the things that has made a difference between Web and Web 2.0 is a technology called RSS (Really Simple Syndication). RSS allows someone to link not just to a page, but to subscribe to it, with notification every time it is updated. In combination with use on portable devices the ability to push not just notices of new blog entries, but also all kinds of data updates as well. This has very relevant application within healthcare to support self care through effective communication between patient and care provider, particularly when combined with the use of home care monitoring devices that will identify to a care provider where a patient requires intervention.

The application of Web 2.0 as a tool for participation has top billing at the next International Conference on Semantic Web and Web Services in July. It will discuss how social networking communities for healthcare are evolving towards becoming user-generated online medical portals and how semantic Web or Web 3.0 is now being developed by adding artificial intelligence to internet services to deliver the next generation of personalised services within healthcare.

### *3.2.2. The Role of Web 2.0 in providing an Interoperability Platform*

One of the key challenges, if not the biggest challenge within the realm of eHealth has been how to support information sharing across organisational and technical boundaries to support the delivery of person centric care. Arguably the revolutionary element of Web 2.0 is concerned with the radically different business model that it offers. In the past the operating system platform procured from a single provider constrained organisations and the individual in their ability to develop application systems and access information across technical and organisational boundaries.

Web 2.0 challenges the dominance of operating systems provided by single software providers, whose massive installed base and tightly integrated operating system and APIs (Application Programming Interface) give control over the programming paradigm [2]. Instead Web 2.0 as a platform is a system without an owner, tied together by a set of protocols, open standards and agreements for cooperation. We can take the Windows Operating Systems as an example and then draw a correlation between the changes taking place in the industry generally with how this is reflected within the context of healthcare.

Windows provided a solution to the problems of the early PC era and solved a host of problems that had previously bedeviled the industry. In the same way single proprietary EPR solutions, where they have been deployed, have been reasonably successful in providing intra-organisational transaction based support for some key business processes. However there has been more limited success in establishing effective solutions for inter-organisational EHR approaches that rely on bringing information together from disparate sources. In the same way as the single monolithic approach controlled by a single vendor, has become a problem generally given the shift to communications-oriented systems which are based on interoperability, co-operation, collaboration and interactivity, the same applies within healthcare. Coupled with the delivery of healthcare related software 'as a service' and the use of open source technologies there are real opportunities to make progress with EHR type solutions.

### *3.2.3. The Application of 'Software as a Service' within Healthcare*

The concept of providing 'software as a service' has been building in momentum over the last few years. In its earlier guise as 'On-demand' services provided by 'Application Services Providers' (ASPs), it took an early foothold within the CRM (Customer Relationship Management) market. Companies such as Salesforce.com have used the advantages of the Web as a platform to enable a software applications delivery model where a software vendor develops a web-native software application and hosts and operates (either independently or through a third-party) the application for use by its customers. Customers do not pay for owning the software itself but rather for using it via an API accessible over the Web.

The traditional application solutions within healthcare haven't typically been conducive to operating this type of model although more innovative solution providers

are moving away from traditional programming technologies to lighter weight web based application development tools to enable them to move to this type of service offering. However the real interest in how SaaS develops within healthcare will be from the new entrants that are beginning to emerge. Tolven is an example of one of these new entrants who are radically challenging the preconceptions about how electronic patient and electronic health record solutions can be delivered using the new technologies enabled by Web 2.0 and the use of Open Source technology. Tolven are already gaining traction in the US in support of the RHIOs and are keen to apply their model in Europe and the UK. Tolven have a ePHR, an electronic Person Health Record and an eCHR, electronic Clinician Record which are brought together by a healthcare informatics platform to enable all healthcare data to be stored and accessed via the ePHR and eCHR solutions. [4] By virtue of the fact that it is based on Open Source technology it is delivered as a service which dramatically reduces the overall cost of ownership.

### *3.3. Open Source Technologies to Support Healthcare*

A few years ago the idea of complex electronic health record solutions being delivered by Open Source technology would have been beyond even the most exposed of 'out of the box' thinking. They are now a serious reality. Open Source Solutions for EPRs/EHRs such as Tolven and OpenEMR are now beginning to emerge which present significant opportunities to resolve some of the problems that have prevented rapid progress towards a comprehensive electronic health record that is person centric and independent of care setting, organisation or service. Tolven and OpenEMR have taken the view that an Open Source, Standards-Based Platform for Healthcare will enable collaboration throughout the healthcare continuum and provides a highly adaptable platform for secure health data management. The inherent features of open source technology promotes the re-use of existing components rather than re-building them and has the significant advantage for healthcare organisations in providing scalability but reducing the cost of ownership [4].

### *3.4. Accessibility to Information*

#### *3.4.1. Mobile Technologies*

Another feature of the recent developments within information technology is in terms of accessibility to information, particularly with regard to information on the 'move'.

The information technology developments within healthcare over the past 20 years have largely been constrained by the fact that electronic information required access via a PC and proprietary software solutions that were confined to organisational boundaries. Little wonder therefore that the more significant advances have been in acute based care and primary based care where the patient goes to the care provider. There has been very little application within community care or in the area of patient interaction and involvement.

Freeing information from the PC and enabling access to information via digital TV, mobile phone or other mobile devices removes this constraint and opens up new opportunities for extending the application of technologies to all care professionals including those that are peripatetic. It is interesting that after only a short time after the highly publicized launch of the iPhone, the application of this type of device is being

promoted as a key tool in the provision of healthcare. The combined application of Web 2.0 technologies including the ability to 'push' information as well as pull and the use of mobile devices provides opportunities for greater interaction between care provider and consumer particularly in promoting self care.

### *3.4.2. Home based Monitoring*

More recently we have begun to see the increased use of technologies that can be used in the home to support self care particularly focused on patients with chronic health problems such as diabetes, COPD (Chronic Obstructive Pulmonary Disease), and cardiovascular disease. Companies like iMetrikus and HealthHero have developed solutions to provide the bridge between biometric data collected through personal health monitoring devices such as blood glucose monitors, insulin pumps and blood pressure monitors to the tools that will allow the use of this data in clinical decision making.

Solutions such as those developed by iMetrikus and HealthHero are based on the premise that if you can provide accurate real time feedback from care professionals to patients based on real measurements from these devices that provide accurate biometric readings then the need for costly attendances for periodic reviews and indeed emergency care can be avoided.

iMetrikus and HealthHero are organisations that have developed solutions that have been very successful in supporting self care. The recent study of the application of iMertikus technology for young patients in Dundee with diabetes, Sweet Talk [5], reported that patients found it a motivating and empowering solution that provided a more collaborative approach to management of their condition.

iMetrikus is a solution that is part of the CfH, (Connecting for Health), Health Systems Demonstrator and is also being used in Wales. The basis of the iMetrikus solutions is about interoperability whereas other medical equipment manufacturers have in the past developed solutions that are not interoperable for example there are numerous blood glucose monitors with phone connections but they are only compliant with a single or limited number of phone systems. The iMetrikus experience in the US has been that this type of solution has to be based on interoperability standards, using 'plug and play' type technology and be low cost (about £150).

## 4. The Challenges in Harnessing New Technologies for Healthcare.

We have looked at some of the recent technologies that are indicative of the transition being made in IT generally which is beginning to change the locus of power from the service provider to the service user and how these technological developments apply within healthcare.

We now need to look at some of the challenges this presents for healthcare providers, healthcare professionals and the healthcare consumer. There are some key issues that can be explored from each perspective.

### *4.1. Challenges for the Healthcare Consumer*

Some of the challenges and issues for the healthcare consumer can be summarised as follows:

- Who owns the data and how is personal data secured?
- How can the consumer be assured of the accuracy and validity of information?

### *4.1.1. Security of Personal Data*

Protection of personal data is an issue both in terms of the use and application of EHRs and also in terms of how personal data is incorporated into Web content. In the context of patient records, if the patient is given access and control of their health record then they have the ability to own it. Giving the patient control of their record may also help to tackle the issues of consent and confidentiality arrangements in that the individual can also potentially control who else can access the record. Clearly there are more complex issues associated with giving the patient full control, particularly with regard to children, mentally ill and elderly patients. However as has been evidenced by the long standing battles in England around how confidentiality and security of the CRS record is to be maintained and managed, putting ownership with an large amorphous organisation (as in the NHS), is not a solution either.

In the US there is a growing demand for Personal Health Records to include the developing concepts of Medical Banking and Health-Records Banks. From the consumers point of view protection of both personal financial and medical information are probably on a par in terms of maintaining confidentiality and ensuring security. The experience of the huge growth of online banking over the past decade clearly has some application within the field of healthcare. This will require however significant developments around structure, access, security and ownership. There is already evidence of this type of approach elsewhere with a growing number of commercial personal health record (PHR) companies competing to take ownership of personal health data. In the Czech Republic, IZIP already has over a million people using its web-based PHR.

If there was any doubt about the importance of healthcare within the industry we just need to look at the recent inroads both Microsoft and Google have made. These titan organisations are already actively participating in ambitious PHR developments as healthcare starts to be seen as a commodity and owning the healthcare consumer presents significant opportunities for technology suppliers. In February this year Google Chief Executive Eric Schmidt announced their new healthcare initiative, stating in the launch, "We're going to partner with leaders in health care to cross-connect... and apply the principles of the Internet to improve the industry...The first principle is, it's the user's data. The data follows the consumer wherever they go…..Google Health aims to untether the two billion X-rays taken in the United States each year, 62 million CAT scans, and other health data, and put them all online for the patients to access". Google's approach aims to store all the health records of a patient and then enable users to import records from different health provider systems, as well as search for doctors and get information on conditions from Google Scholar, discussion groups, and other sources. Third-party developers are being encouraged to create gadgets that can be embedded in iGoogle home pages for things like alerts to remind patients to take their medicine, and to create interfaces for example to display a weekly view of all the medicines a patient takes.

There are no easy solutions in terms of tackling security and confidentiality for patient information, particularly where sharing of information is also a key requirement within healthcare. It would appear however that for a vast majority of consumers placing ownership of personal health information has to reside with the subject of that

information. The question is however, with organisations like Google and Microsoft competing to 'own the user' in terms of tying them in to use of their platform, can they really be the trusted custodians of personal health data?

#### *4.1.2. Ensuring the Validity and Accuracy of Information*

The now well known phrase that on the Internet, 'nobody knows you are a dog—or an idiot', is clearly a real concern when applied within the context of healthcare. From the surveys conducted however on the use of the internet to access valid healthcare information it would appear that although user-generated information offers consumers more health options, the upside largely outweighs the risk. A survey by the Pew Internet & American Life Project in Washington, DC states that nearly one-third of the 100m Americans who have looked for health information online say that they or people they know have been significantly helped by what they found. In contrast, only 3% reported that online advice had caused serious harm [3].

A lot of user-generated health information is accurate. A panel of neurology specialists judged that only 6% of information posted in the epilepsy-support group of BrainTalk was factually wrong, according to a study published in 2004 in the *British Medical Journal*. With enough people online, misinformation is often quickly corrected. Gilles Frydman, the founder of Association of Cancer Online Resources (ACOR) claims that inaccurate posts on the ACOR website will be pointed out within two hours [3].

However as has been seen in other sectors the battle to become the trusted source of information is already beginning with regard to healthcare information. As companies begin to realise that control over data may be their chief source of competitive advantage, we will see heightened attempts at control of key consumer groups, healthcare will be one of these. The winners will be the companies that reach a critical mass via user aggregation, and who are able to turn that aggregated data into a system service. As we have explored in respect of personal data, if there was any doubt that healthcare is seen as a key sector that companies are keen to dominate, Microsoft's acquisition of Medstory Inc is clear evidence. Medstory has developed search software that applies artificial intelligence techniques to medical and health information in medical journals, government documents and on the Internet. Peter Neupert, vice president for health strategy at Microsoft, is quoted as stating this acquisition was a first step in a broader company strategy to assemble technologies that will "improve the consumer experience in health care." Microsoft clearly see one important ingredient in its plan will be a specialized search engine tailored to deliver useful medical information to consumers.

### *4.2. Challenges for the Healthcare organisation in enabling Consumer Participation:*

Some of the challenges and issues for the healthcare organisation can be summarised as follows:

- Who funds the cost of enabling technologies?
- Given the growing diversity in terms of healthcare provision how do organisations balance the need to maintain continuity and efficacy of care with the need to gain competitive advantage?
- How do you keep pace with developing technology to achieve improved care?

#### *4.2.1. Funding Participation of the Consumer*

The challenge for Healthcare organisations in seeking to enable the participation of the consumer is in ensuring equity. Depending on whether there is a socialised or an insurance led health system will give rise to different interpretations of equity and different challenges.

In the US which typifies the insurance based model there are potentially conflicting interests between the consumer and the care professional. A physician is incentivised by the system to carry out a procedure or deliver a treatment in order to receive payment. This may or may not be the best course of action for the patient. There is also no incentive to collaborate with other healthcare professionals in delivering a holistic plan of care. Clearly there will be a temptation to 'influence' the consumer in this model with regard to how they access information; as a consequence there is a danger that funding the ability of the consumer to participate will be influenced by this.

In the socialised health care system typified by the NHS there are different challenges. If organisations establish the sole route to participation through technology then it follows that there will be an expectation, if not an obligation, within a socialised system to ensure equal access for all recognised participants. In some areas that we have discussed this may be relatively straightforward. In the case of home monitoring for chronic diseases for example there is the potential for huge cost savings for the organisation as well as benefits for the patient and there is arguably a clear business case which will enable funding of appropriate devices. Where it becomes more difficult is with regard to provision of universal access to personal health records however this may be facilitated.

#### *4.2.2. Balancing the need to maintain continuity of care with the need to gain competitive advantage.*

As we have explored above where there is a need to seek competitive advantage through the provision of information or access to information, there will always be the desire to tie the consumer into a particular service or brand. This has the potential to conflict with the need to share information across healthcare providers and in encouraging collaboration between providers in the best interest of the consumer as opposed to the best interests of the provider.

#### *4.2.3. Keeping Pace with Technological Development.*

The other challenge for organisations is in keeping pace with technological development. The simplest answer to this is that organisations, particularly ones such as the NHS, cannot hope to keep pace with technological development. As Jon Hoeksma observes, 'If Web 2.0 has one unifying concept, it is that the technologies involved are radically disruptive, economically, socially and technologically. Web 2.0 networks are grown from the ground up – gaining strength from their membership. They are the antithesis of top-down, centralist initiatives that set fixed objectives and boundaries' [6]. The pace of populist technological change gives the opportunity to the consumer to dictate the way organisations need to interact with them rather than the other way round. The best organisations can hope to achieve is to identify the technological advances that provide the best opportunity for supporting the delivery of their services and attempt to come close to meeting consumer expectations. To achieve

this organisations need to be responsive and nimble in their approach to harnessing and utilising new technologies.

It is hard to see therefore how the 10 year Programme for IT in the UK can be nimble and responsive when it's highly centralised approach is fundamentally designed from the top-down. The Titanic NPfIT is by definition slow and uncompromising. Meanwhile the express train of Web 2.0 has already left the station.

### *4.3. Challenges for the Healthcare Professional:*

- How do they respond to the growing knowledge consumers have about their own healthcare?
- How do they adapt their work practice to enable more of a collaborative approach to the provision and management of care that involves consumer and other care professionals?

#### *4.3.1. Responding to the 'Participative Consumer'*

Healthcare professionals are beginning to come to terms with the 'informed patient' and many professionals see the opportunities in encouraging consumers to extend their knowledge of their own condition and also the opportunity to extend that of professionals as well. Daniel Hoch, professor at Harvard Medical School who helped to found BrainTalk, suggests that many doctors, "don't get the wisdom of crowds." [3]. But he thinks the combined knowledge of a crowd of his patients would be far greater than his own. A wiki capturing the knowledge of a cohort group of individuals with the same condition could be invaluable not only to others with that condition, but also to the medical professionals who care for them. The aggregation of knowledge has advantages for all participants in the delivery of care.

The danger that this presents is in the potential of the 'wisdom of the crowds' turning into the 'madness of the mobs'. The next generation of development, labeled Web 3.0 may address this. Web 3.0 describe an evolutionary path for the Web that leads to artificial intelligence that can reason about the Web in a quasi-human fashion. Companies such as IBM and Google are implementing new technologies that are yielding surprising information such as making predictions of hit songs from mining information on college music Web sites. There is also debate over whether the driving force behind Web 3.0 will be intelligent systems, or whether intelligence will emerge in a more organic fashion, from systems of intelligent people, such as via collaborative filtering services like del.icio.us, Flickr and Digg that extract meaning and order from the existing Web and how people interact with it. [7]

Healthcare professionals ignore the 'participative consumer' at their peril. Their dilemma is clearly one 'if you can't beat them join them' and the ability of healthcare professionals to embrace both collaboration with the consumer, other healthcare professionals and the community of individuals who share the same healthcare need will become a pre-requisite in meeting the consumer expectation.

#### *4.3.2. Adapting Working Practice to enable participation*

Healthcare professionals will also need to adapt their working practices and processes to accommodate the participative consumer. There will need to be a shift from consumer/professional interaction being solely at the convenience of the professional to

a more balanced situation that takes into account the consumer's requirements and indeed choices. In the UK the traditional role of the GP as the gatekeeper is likely to be challenged as consumers become more aware of the services and choices open to them.

## 5. Conclusion

The application of developing technologies within the context of healthcare offers huge potential to improve the consumer's experience whether this is to support health improvement or illness. Some of the benefits include:

- Increased self care enabling reduction in hospitalisation and improved control by the patient of their own care.
- The use of Web 2.0 services increase patient participation and patient empowerment.
- The ability to gain better access to information on options for care allows the potential for greater choice for the patient.
- The application of Software as a Service and the use of open source technologies present significant opportunity to accelerate the development of electronic patient and health records.

In order to exploit these benefits however, information systems strategies for healthcare must focus on the ability to link the health events of a service user as well as enabling the drawing together of the experience of similar patients in order to develop a shared knowledge base. This requires an information architecture to support information sharing. It will require a multi-layered architecture built around standards that allows the capture and sharing of person specific and disease specific content. This needs to be done in an affordable way and therefore needs to incorporate existing systems in the traditional providers to co-exist with new systems as defined by Web 2.0.

## References

[1] Coopers and Lybrand European Healthcare Group (1997) Information Management - The Key to Managed Healthcare in Europe
[2] What Is Web 2.0, Tim O'Reilly, CEO of O'Reilly Media
[3] Health 2.0, The Economist, Sep 6th 2007
[4] www.tolvenhealth.com
[5] A randomized controlled trial of Sweet Talk, a text-messaging system to support young people with diabetes Franklin VL, Waller A, Pagliari C, Greene SA.
[6] Health 2.0 and the future of the NHS, Jon Hoeksma, 19 October 2007
[7] en.wikipedia.org

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# Active Ageing: Independence through Technology Assisted Health Optimisation

B.R.M.MANNING [a], J,.McCANN [b], S.BENTON [c], J.BOUGOURD [d]
*a University of Westminster, School of Informatics*
*Bryan.Manning@btinternet.com*
*b University of Wales, Newport, Smart Wearables Research Group*
*jane.mccann@newport.ac.uk*
*c University of Westminster, Business Psychology Centre*
*bentons@wmin.ac.uk*
*d University of the Arts, London*
*j.bougourd@fashion.arts.ac.uk*

**Abstract.** The potential doubling in the percentage of the elderly within the populations of Europe and beyond over the next decades has focused informatics research on the development Assistive Technologies and Smart Homes. However its concentration on creating a supportive home environment also has the potential for makings its users over dependent on its facilities and as a result trapped within it.
This paper outlines an approach that extends the smart homes concept out into the wider community to create a smart environment that not only maintains contact with all their home-based services, but also expands these to include other facilities needed to assist them whilst on the move. This involves the convergence of physiological monitoring, communications and computing with leading-edge textile technologies, which uses a multi-layered, multi-functional clothing system as a mobile and extended variant of a smart home IP hub. In addition to variable functionality capabilities of the clothing layers in terms of thermal, shock-absorbent and other characteristics, wireless IP connectivity is provided between layers with external links typically being WiFi enabled. Health optimisation is provided by on-going lifestyle guidance/action feedback based on auto-diagnostic analysis.

**Keywords,** Smart Wearable Garment technologies, remote physiological monitoring, diagnostic trend analysis, mobile IP links, WiFi, motivation behaviours.

## Introduction

The recognition of the impact of the potential doubling of the percentage of the over 60s in Europe and beyond has been the subject of increasing concern and research activity for some time. Much of this activity has centred on the development of the Smart Home concept with the support of the European Commission through the COST219 set of programmes and latterly by various initiatives in the areas of Ambient Assisted Living.

These effects have led to an increase in the take up of commercial telecare systems and services in the UK and elsewhere, together with a trend towards their convergence with those from the telehealth domain. However its adoption by the bulk of this segment of the population remains largely blighted by the perception that it stigmatises and sidelines them out to the periphery of their home communities.

This cultural rejection is not helped by the unappealing techno-clinical look and feel of many of the designs, which reinforces an image of its user's impairment and infirmity that strikes at the heart of their self-esteem. A far deeper understanding of these demotivational issues is needed to redress this balance to the point that they are far more prepared to look for and accept appropriate support systems, which they can see as life enhancing rather than finding it inflicted upon them [1].

This is borne out by the response to action taken by West Lothian Council in Scotland [2] in providing all over 60s with a basic Smart Home technology service package. This innovative "mainstreaming" approach was widely welcomed as it was seen as supporting a continuing safe, secure and independent lifestyle within their own home community. It also went a long way to dispelling the idea that the elderly as a group are overly technophobic. The key lesson is that whilst technology can enable change – effective change is essentially driven by perceived benefit delivered at minimum risk or inconvenience.

## 1. The Self-Care Environment

Whilst the continued development of Smart Home scenario services [see Figure 1] to cover the whole range of health and social care [3] is of great potential benefit, the undoubted advantages that they can bring also carry the seeds of increasing dependency. The study in West Lothian identified this as a significant risk factor where excessive well-meant help by carers was found to disempower their clients by creating a dependency culture.

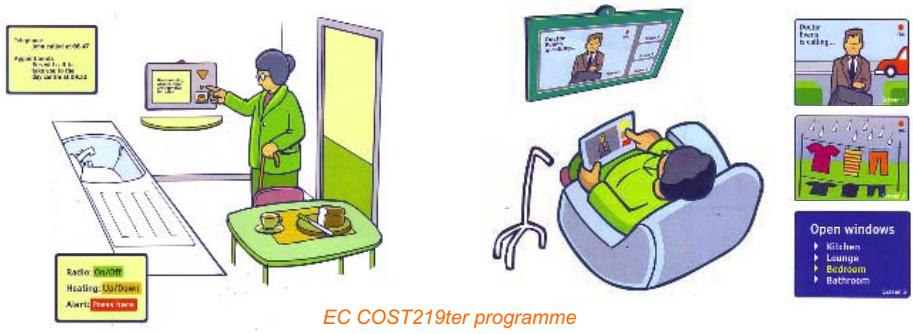


**Figure 1**. Smart Home Scenarios

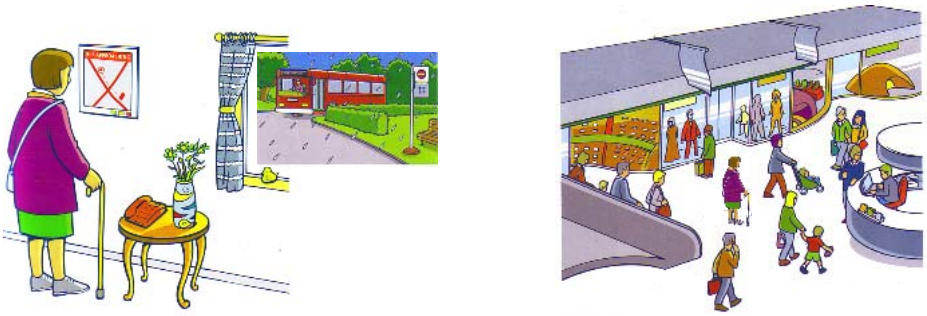


**Figure 2**. Going Out into a Smart Environment

The obvious implication of this is that support systems functionality needs to be carefully balanced against user capability. This needs to be assessed and adjusted on a regular basis to cope with advancing infirmities without inhibiting as active a lifestyle as possible.

An active independent lifestyle implies freedom of movement to go anywhere within reason whilst still having access to home support systems together with additional travel-oriented ones [4]. This would expand the Smart Home concept out into a wide range of Smart Environment scenarios, as seen in Figure 2.

Achieving this requires a shift away from a static to a mobile system platform hub approach enabled by miniaturised devices, sensors and wireless communications. As any form of separate pack is clearly impractical, the platform itself has to be an integral part of the users clothing.

This has led directly to the development of a three-component clothing layering system [5] designed to meet the varied needs of older people wherever they choose to be. As clothing is a highly personalised issue, its attractiveness, comfort and ease of use will be a key critical success factor for it acceptability.

Each layer will combine advanced textile technology with miniaturised devices, sensors and transmitters linked within each garment to form a distributed wireless IP hub that is automatically configured to suit the wearer's needs and location as they dress themselves.

Within the home the inner layers communicate with the home IP Portal via Bluetooth or similar short-range systems. When outside this link extends to include the outwear, which provides wireless IP links to remote service providers. This will use either WiFi or similar systems [6] [7] with suitable coverage with subsequent links over landlines [see Figure 3].

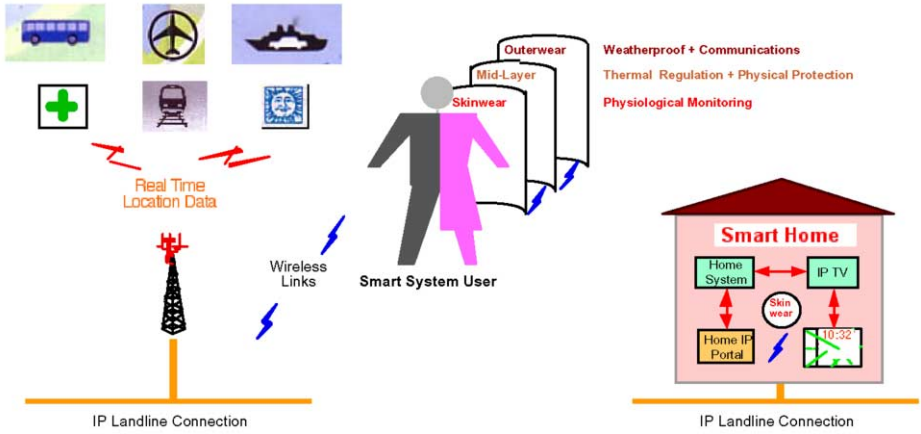


**Figure 3**. Multi-layered Smart Mobile Platforms

## 2. Health Optimisation

The aim of the "skinwear" physiological monitoring system is to detect latent or early stage symptomatology trends that have the potential to be countered, halted or even reversed.

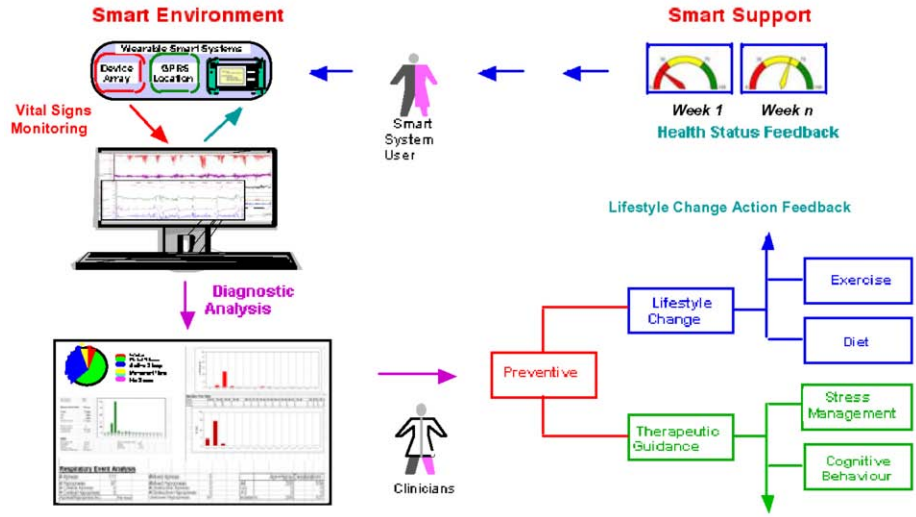


**Figure 4**. Physiological Monitoring enabled Lifestyle Improvement

The approach centres on the analysis of continuous monitoring of heart rate variability and respiration to identify early indications of a downward slide towards a chronic condition evidenced by decay in amplitude and changes in waveform structures. Preventive action to reverse these trends is based on a clinically managed "drip-feedback" of a mix of lifestyle change in dietary and exercise routines, coupled with a range of therapeutic guidance procedures, provided back to the patient via the appropriate IP links [Fig.4].

## 3. System Design and Infrastructure

As an in-depth understanding of the motivation and lifestyle interests of the active ageing is central to the success of the concept, an ongoing in-depth study of the behavioural attitudes is central to informing and directing the design process of both the clothing and the service requirements [see Figure 5].

These then set the needs of the underlying IP communications/computing infrastructure in terms of the home and community environments, together with multiple services provision.

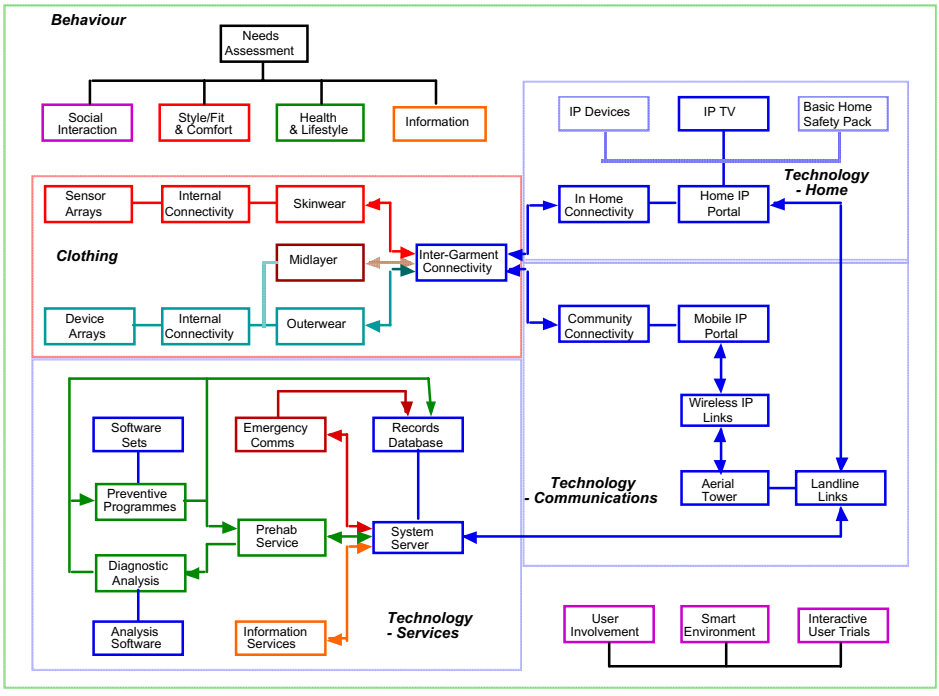


**Figure 5**. System Development Infrastructure

Whilst the Smart Home is an integral part of the overall systems architecture, the variety and complexity of available products and subsystem has been drawn together for the purposes of this paper under a generic heading of devices together with a basic home safety pack. They would be bundled together to link outward with all external services as a combined IP hub and portal.

Voice and visual communications at home and on the move will be IP based. Within the home this would be either via IPTV sets or handheld devices, whereas on the move the aim is to in-build this into the garment together with other location related devices. In essence this will involve distributing elements derived from mobile phone and PDA technology appropriately within the structure of the outerwear. The intention is to provide a test-bed for an emerging range of integrated textile-based electronic products – in particular crush-resistant screens and similar components.

Connectivity on the move will make use of the increasing WiFi and WiMax technology coverage in urban areas, whilst remaining in the position to utilise future wireless IP service developments.

Although the provision of an effective health optimisation process is the primary objective, its acceptability will depend in substantial measure on providing attractive, easy to access and use, multi-functional services that support and enhance maintaining a mobile lifestyle. This is particularly true where locating facilities such as pharmacies, support centres or public transport services are concerned. These services will be free with interactive access concentrated via a single server hub during trials, but longer-term service funding/charging options will also be examined as part of the overall scheme.

## REFERENCES

[1] Benton S and Manning B (2006) .Assistive Technology - Behaviourally Assisted, Medical and Care Compunetics 3, IOS Press, June 2006, ISBN 1-58603-620-3.

[2] Bowes A and McColgan G (2006) Smart Technology and Community Care for Older People:Innovation in West Lothian, Scotland, Age Concern Scotland, August 2006. ISBN 1-874399-99-9.

[3] J.Gill (Eds.). Making Life Easier. COST219. 2005. ISBN 1-86048-031-3.
www.tiresias.org/cost219ter/making_life_easier/making_life_easier

[4] Manning B, McKeon Stosuy M, Layzell B, Madani K. e-Care: An assistive technology enabled paradigm shift. Smart Homes and Beyond – ICOST 2006, 4th International Conference on Smart Homes and Health Telematics, Belfast, Northern Ireland. ISBN 1-58603-623-8.

[5] McCann J., A design process for the research and development of Smart Clothes with embedded technologies with potential to enhance quality of life for older people. Smart Homes and Beyond – ICOST 2006, 4th International Conference on Smart Homes and Health Telematics, Belfast, Northern Ireland. ISBN 1-58603-623-8.

[6] Intel White Paper. Understanding WiFi and WiMax as Metro-Access Solutions. www.intel.com/netcomms/technologies/wimax/304471.pdf

[7] Roe P.R.W (Ed), Bridging the Gap.? Access to telecommunications for all people.Commission of the European Communities. Presses Centrales Lausanne SA, November 2001.

# Empowerment

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# Populomics

M.C. Gibbons MD, MPH
*Johns Hopkins Urban Health Institute*

**Abstract** Increasing evidence suggests that socio-behavioral factors are more important determinants of healthcare outcomes than historically recognized. In addition, the US healthcare system is primarily oriented to acute, hospital based, disease treatment. As such, responding adequately to the health and healthcare needs of both non-hospitalized and hospitalized patients with chronic diseases is proving difficult. Improving population level health problems like healthcare disparities is also challenging, in part because of this complex interplay of socio-behavioral, community and biologic factors within the context of the current healthcare system.
Recent advances in the computer sciences and information technologies have spawned several methodologic advances in the biological, molecular and clinical sciences (eg, DNA chip technology and microarray analysis), enabled quantum leaps in molecular and submolecular medicine, and catalyzed the emergence of whole new fields of study such as proteomics, and genomics. With the emergence of Populomics, the behavioral and population sciences are on the verge of a similar information technology–based scientific revolution. Integrating knowledge from the molecular sciences to the population sciences has the potential to propel health and disease inquiry, treatments and interventions well beyond current limitations, to yield insights and advances not currently possible. This paper briefly discusses the conceptual origins, theoretic basis and the future potential of this field.

## Background

Increasingly, scientific evidence suggests that disease causation results from complex interactions of social, environmental, behavioral and biologic factors which simultaneously and often cooperatively act across more than one level of existence over time [1]. Thus a comprehensive understanding of health and disease requires the integration of knowledge derived from the bench, sociobehavioral and population sciences. Most historic and contemporary conceptual models of health though, have often been derived either from the socio-behavioral sciences *or* the biomolecular sciences. With the exception of those pathways based on stress (neuro-immunological) mechanisms, the published frameworks in the behavioral sciences and epidemiological literature largely lack clearly stated, causal biologic connections to observed health outcomes[2-6]. On the other hand, most biologically oriented formulations poorly account for socio-environmental and behavioral effect modifiers that may profoundly influence the pathogenesis of disease and the development of health disparities [7-10].

To complicate matters further, scientists and investigators trained in the clinical and bench sciences are generally taught to consider only discreet, quantitative exposures (viral, bacterial, toxicological, psychological etc.) as etiologic agents of disease. Historically they have primarily studied these etiologic agents in isolation from the broader socio-behavioral contexts in which they exist. Social and behavioral scientists though, often consider more qualitative factors like poverty, socioeconomic

status, and racial segregation as key determinants of health [11;12]. Usually most social scientists only consider other more quantitative exposures as factors which alter the nature of the association between a social factor and a given health outcome [13]. Most socio-behavioral scientists also study etiologic factors in isolation from the biophysiologic and/or molecular genetic mechanisms on which living organisms depend.

Because scientific investigation has historically progressed along these two largely parallel perspectives, the domain of clinical medicine, which largely derives from the biophysiologic and molecular genetic sciences, has been largely concerned with a hospital based, individualized approach to health and disease. On the other hand the domain of Public Health has historically been that of populations in communities. In the past, this dichotomy has indeed served science well and has rapidly led to many scientific advances in knowledge. Today however, healthcare challenges related to the burgeoning proportions of elderly citizens in the US and the widespread documentation of racial and ethnic disparities in healthcare, are suggesting the need to reconsider the dichotomization of the role of sociobehavioral and community factors in healthcare research and clinical medicine. Elderly patients often suffer from multiple chronic diseases for which they are taking several medications. They may need in home and community based health "support" services but may not need to be hospitalized. Consequently more family and community residents are becoming "caregivers" and "care providers" This shift is enhancing the impact of social, behavioral, community and economic realities on their therapeutic regimens and provider relationships. In short, the social and behavioral sciences, which traditionally had not been considered within the domain of healthcare, are increasingly recognized as fundamentally linked to illness, health and healthcare outcomes [14]

While the need for an integrated approach to health research and health care is gaining appreciation, thinking across disciplinary lines can be challenging. Recently the Sociobiologic Integrative Model (SBIM) model has been proposed as a conceptual transdisicplinary research construct that provides for biologically driven conceptual integration of both socio-behavioral and biomolecular concepts known or hypothesized to influence disease pathogenesis in individuals and among populations [1]. As such, the SBIM facilitates organization of heterogeneous clinical, biological and socioenvironmental data elements from in relation to the biomolecular mechanisms through which they must operate, to impact health outcomes.

Finally, the growing realization of healthcare disparities is forcing clinical researchers to think about disease causation not only among individual patients, but also across entire groups or populations of people. Among patients who have vastly differing cultural beliefs and practices, diets, educational or literacy levels and socioeconomic resources, clinical practitioners and researchers developing interventions that ignore these sociocultural realities may struggle to demonstrate or maintain therapeutic efficacy across increasingly multicultural populations of patients.

## Transdiciplinarity and the Role of Health Information Technology

Disentangling the myriad determinants of disease and the biomolecular mechanisms through which they operate, especially within the context of health care disparities, cannot comprehensively be accomplished in the absence of a transdisciplinary approach nor without a significant reliance on the computational and information

sciences. In the last decade, advances in computing and information sciences have been the catalyst for several methodological leaps in the biological and molecular sciences (eg, DNA chip technology, and genome wide association studies), and sped the emergence of whole new fields of study (metabolomics, proteomics, and regulomics) in the clinical and bench sciences.

Similarly, the potential also exists for similar information and communication technology (ICT) based advances [15;16] among public health physicians, those practicing in areas of social medicine and healthcare disparities researchers. In addition to improving the efficacy of current clinical interventions, new technology based tools may facilitate the analysis and interpretation of population level data to enable the development of "community [population] arrays" or community-wide risk profiles based on clinical and socioenvironmental data. This population-level risk characterization could potentially go beyond the limitations of current analyses and yield insights distinctly different from those based on current epidemiologic or sociobehavioral methodologies [17]

The term Populomics has emerged from the synthesis of the Population sciences, Medicine and Informatics [16;17]. Populomics is defined as an emerging discipline focused on population level, transdisciplinary, integrative disease/risk characterization, interdiction and mitigation that rely heavily on innovations in computer and information technologies. Populomics seeks to characterize the interplay of socio behavioral pathways and biophysiologic and molecular mechanisms which work across levels of existence, to impact health particularly, at the population level.

## Discussion

Sociocultural and environmental realities are suggesting the need for integrated approaches within contemporary healthcare. Although overcoming the historic inertia towards dichotomization of the biomedical and social sciences may be challenging, informatics offers the promise of being a catalytic agent for scientific innovation in healthcare among populations. While in some ways similar to Public Health informatics, Populomics is distinct in that it specifically focuses on the integration of medical and social sciences to foster the elucidation of the biophysicologic and molecular mechanisms that under gird socioenvironmentally determined outcomes among populations. In many ways Populomics research builds on the best of centuries of extraordinary scientific and clinical advances and extends these by highlighting the need to focus on the *relationships* between groups of socioenvironmental factors and the underlying mechanisms which operate in communities and among populations. In so doing it may lead to tools and methodologies to identify subpopulations that are superior to contemporary approaches of delineating subpopulations of people based on race, socioeconomic status, educational status or genetic mutations. Finally, in the future, therapeutics derived from populomics oriented research may significantly improve our ability to promote health, provide high quality healthcare to every citizen and in so doing, eliminate racial and ethnic disparities in healthcare.

## References

[1] Gibbons MC, Brock M, Alberg AJ, Glass T, LaVeist TA, Baylin SB et al. The Socio-biologic integrative model: Enhancing the integration of socio-behavioral, environmental and bio-molecular knowledge in urban health and disparities research. Journal of Urban Health 2007; 84[2]:198-211.
[2] Macintyre S. The Black Report and beyond: what are the issues? Soc Sci Med 1997; 44[6]:723-745.
[3] Acheson D. Independant Inquiry into Inequalities in Health. 1998. London, England, UK Department of Health.
[4] Williams DR. Race, socioeconomic status, and health. The added effects of racism and discrimination. Ann N Y Acad Sci 1999; 896:173-188.
[5] LaLonde M. A new perspective on the health of canadians. 1981. Government of Canada.
[6] Evans RG, Stoddart GL. Producing health, consuming health care. Soc Sci Med 1990; 31[12]:1347-1363.
[7] Burger R, Gimelfarb A. Genetic variation maintained in multilocus models of additive quantitative traits under stabilizing selection. Genetics 1999; 152[2]:807-820.
[8] Phillips TJ, Belknap JK. Complex-trait genetics: emergence of multivariate strategies. Nat Rev Neurosci 2002; 3[6]:478-485.
[9] Sharma AM. The thrifty-genotype hypothesis and its implications for the study of complex genetic disorders in man. J Mol Med 1998; 76[8]:568-571.
[10] Meyer JM, Breitner JC. Multiple threshold model for the onset of Alzheimer's disease in the NAS-NRC twin panel. Am J Med Genet 1998; 81[1]:92-97.
[11] Berkman LF, Kawachi I. Social Epidemiology. New York: Oxford University Press, 2000.
[12] LaVeist TA. Race and Health. San Francisco: Jose-Bass, 2002.
[13] Amick BC, Levine S, Tarlov AR, Walsh DC. Society and Health. New York: Oxford University Press, 1995.
[14] Singer BH, Ryff CD. New Horizons in Health: An Integrative Approach. Washington, DC: National Academy Press, 2001.
[15] Gibbons MC. A historical overview of health disparities and the potential of eHealth solutions. J Med Internet Res 2005; 7[5]:e50.
[16] Abrams DB. Applying transdisciplinary research strategies to understanding and eliminating health disparities. Health Educ Behav 2006; 33[4]:515-531.
[17] Gibbons M.C. eHealth Solutions for Health Care Disparities. New York, NY: Springer, 2007.

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# Virtual Health Platform for Medical Tourism Purposes

Debora MARTINEZ [a], Pedro FERRIOL [a], Xisco TOUS [a], Miguel CABRER [b] and Mercedes PRATS [a]
[a] *e-Government, e-Business and e-Health, Fundació IBIT, Spain*
[b] *Innovation, Research and Communication Consulting, S.L., Spain*

**Abstract.** This paper introduces an overview of the Virtual Health Platform (VHP), an alternative approach to create a functional PHR system in a medical tourism environment. The proposed platform has been designed in order to be integrated with EHR infrastructures and in this way it expects to be useful and more advantageous to the patient or tourist. Use cases of the VHP and its potential benefits summarize the analysis.

**Keywords.** Health Tourism, Personal Health Record, Interoperability, Business Models.

## Introduction

Medical or health tourism has increased highly during the last years. Consequently, a large number of patients from worldwide countries have travelled to other countries in order to receive medical care, mainly motivated by three reasons:

- The economic cost of operations is much more affordable than in the own country. Some of the most requested operations are related to orthopaedics, cardiology, ophthalmology and plastic surgery.
- To avoid the long waiting lists in their country.
- Typical tourist destinations allow the patient to enjoy a pleasant recovery holiday, because of its tranquillity during the low season, the quality of its tourist amenities, etc.

Nowadays, different services that offer medical tourism packages exist. This kind of packages include the trip, operation and accommodation, most of them especially to Asian countries like Thailand, India and Singapore (which are the three most important medical tourism destinations in the World) and to other places like Germany and the Middle East.

Because of this situation, the need of interoperability and use of communication standards between the different health information systems in an international context has come up. This along with the beginning of the Personal Health Record system has developed the origin of a new international health system model.

At the moment, some projects have taken the first steps in this field. One of them is the Traveler's Electronic Health Summary Template (TET)[1], which establishes a

standardized Personal Health Record (PHR) system that can be stored in portable devices (USB disk, smart card or CD) and it's designed to achieve interoperability between the different countries forming the Asia-Pacific Economic Cooperation (APEC).

Also recently, the Health Level Seven (HL7[1]) organization published the draft for a PHR functional model standard[2], defining its features and interoperability guidelines. The Integrating the Healthcare Enterprise (IHE) initiative also includes in its profiles the XPHR (Exchange of Personal Health Record Content), which defines the standards to manage the information exchange between the PHR systems used by patients and the EHR (Electronic Health Record) used in health care centres.

Other systems that offer to patients the means to create and maintain their own PHR are MedKey[3] and CapMed[4], which also support its storage in portable devices, although they're not specifically focused in tourists. We can also find Microsoft's HealthVault[5] and the more recent miVitals[6] and the new service related to health that Google is developing (Google Health), which will include the PHR amongst other features.

Furthermore, there are some health related Web 2.0 tools like PatientsLikeMe[7] or Patient Opinion[8], that allow to share personal experiences about diseases and health care centres, respectively. This kind of social networks is achieving to awake patients' interest in using new technologies in order to improve their quality of life.

In spite of everything, the use of PHR is still low. The main reason is that many people are still concerned about PHR's privacy and security and think they will have difficulties to learn how to use it.

## Virtual Health Platform description

The most important fact about Personal Health Records is that they must be up to date to be really useful, so, their interoperability with other information systems becomes essential. The platform analyzed in this publication is expected to offer a solution to this matter.

The Virtual Health Platform (VHP) is very simple to learn, easy to use and all its information is understandable to patients, which can be a good reason to promote and increase the PHR use among the still sceptical patients.

The main innovation of the VHP is not the technology used, but the use model based on the tourist sector, specifically on Medical Tourism.

The platform consists of two modules (see Figure 1):

- A Personal Health Record (PHR), which contains basic and relevant medical information of the patient (diagnosis, medication, allergies, etc.) codified in SNOMED[2], improving the management of patients' medical information.

[1] HL7 (Health Level Seven), is an all-volunteer, not-for-profit organization involved in development of international healthcare standards. "HL7" is also used to refer to some of the specific standards created by the organization (i.e. HL7 v2.x, v3.0, HL7 RIM etc.).

[2] SNOMED CT® (Systematized Nomenclature of Medicine -- Clinical Terms), is a systematically organized computer processable collection of medical terminology covering most areas of clinical information such as diseases, findings, procedures, microorganisms, pharmaceuticals, etc.

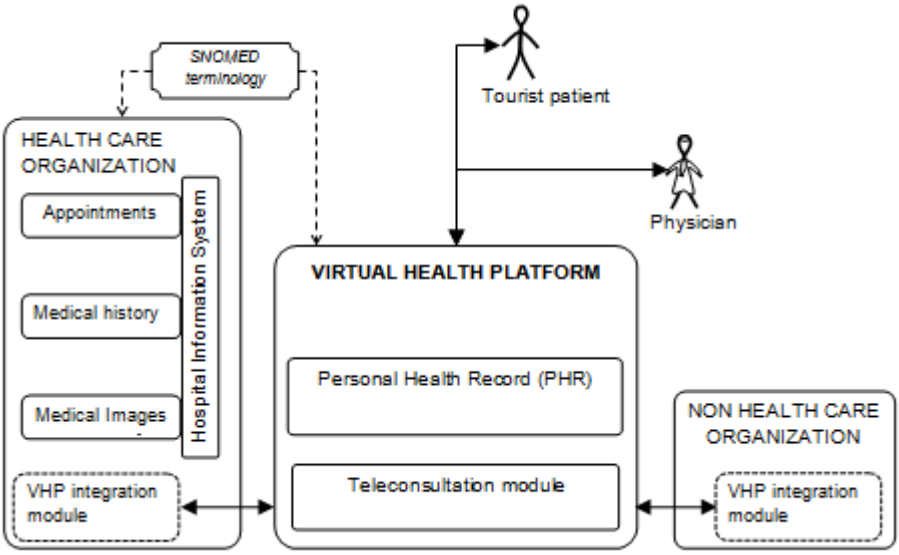


**Figure 1.** Virtual Health Platform architecture

- A virtual asynchronous Teleconsultation solution that allows physicians to access to the data patient, to ask for a second opinion, to refer a patient for care or to make an appointment. This module makes possible to exchange information including images and videos codified in DICOM[3].

SNOMED and DICOM standards are used for interoperability reasons. On the one hand, SNOMED allows users to read and to add information in their own language, because the standard performs the appropriate translations and all the medical data stored is codified. On the other hand, the DICOM standard allows to exchange medical images between different information systems avoiding problems related to interoperability.

The platform implements an integration model with other systems using Health Level Seven (HL7) messages or Web Services. The VHP will be able to communicate with health care organizations and other places like hotels, resorts, sailing clubs and tourist centres in general, and it will be accessible on the Internet by tourist patients, physicians and other authorized users. Moreover, patients can store their relevant medical information into portable devices like USB or memory cards.

This kind of technology can even facilitate the creation of new medical tourism business models, making easy mobility and health coverage of patients worldwide and promote and increase PHR use, studying its integration capacities especially with EHR systems.

The platform allows covering the next workflow:

[3] DICOM (Digital Imaging and Communications in Medicine) is a standard for handling, storing, printing, and transmitting information in medical imaging. It includes a file format definition and a network communications protocol.

- A patient that is going to travel can store critical data on the Virtual Health Platform. If the patient is travelling as a consequence of a medical tourism process, he or she can also make a teleconsultation and send pre-surgery information or images.
- When the source health care institution receives the information, a teleconsultation can be managed and an appointment with the patient can be made.
- In order to treat the patient, physicians can access to the Personal Health Record of the platform and get the information in any language (SNOMED performs the translation of the medical information).
- If there is an emergency or problems connecting to the platform, the medical information can be reviewed through the USB device or memory card of the patient.
- When the patient has already been treated and goes back to his country, the new information is stored in the platform's Personal Health Record.

## Virtual Health Platform use cases

Three business models focused on a medical tourist environment have been taken into account to promote the Virtual Health Platform adoption and, in some way, to improve the patient's quality of life.

*Full Health Assistance Services*

This model will make possible free worldwide movement assuring an improved international health care system to the tourists. Through VHP health care providers can review the supposed injured tourist's health data (entered previously by the patient through the VHP), an information that could be relevant to decide the optimal treatment.

*Improvement of access to Health Care Providers*

This model allows the patient easily access to renowned specialized clinician offices and to avoid the long waiting lists in their country. In this case, the potential 'tourist'-patient who needs, for example, a surgery could make an appointment with the interested clinician office. The VHP enables the interoperability between the own patient's local physician and the selected specialist who will be able to refer and to review remotely all the patient necessary pre-surgery and post-surgery tests and examinations stored on the VHP by the local physician.

*Health Services and facilities on Tourist destinations*

This model offers patients to recover in a pleasant and helpful environment providing medical services that allow their health monitoring. Before travelling, patients can enter their relevant health parameters on the VHP so during the sojourn they will be assisted through the teleconsultation VHP's function.

A representative example combining these models is described below:

A patient suffering from cataracts decides to have the operation in a foreign country, advised by his family doctor or on his own initiative. The main reasons of his decision could be: to avoid the long waiting lists in his country, the affordable price of the operation, the prestigious specialists in that country and the possibility of having a pleasant recovery holiday.

At home, the patient accesses to the Virtual Health Platform and inserts all his relevant medical data using the Personal Health Record module. He could also store the main information in his USB device, if he has one at his disposal. His family doctor also accesses to the Virtual Health Platform and communicates with the specialist from the country where the patient's going to have the operation though the Teleconsultation module, sending all the necessary tests, images and pre-surgery information. The patient could also choose, using the Virtual Health Platform, the hotel where he wants to stay.

Once in the foreign country, the patient's health state can be controlled regularly at the hotel before and after the operation and, in case of emergency, his basic medical data can be retrieved anywhere using his USB device. When the patient goes back to his country, his Personal Health Record will have been updated with all the tests, images and post-surgery information.

## Virtual Health Platform Expected Benefits

A successful implementation of the Virtual Health Platform would improve and facilitate communication among several health care institutions (like hospitals, clinician offices and other organizations) allowing an interoperability model in an international context and hence providing a better health care assistance services for patients. Other benefits are:

- Diversification of tourism offers and promotion of high quality tourism, like it is medical, in the different international tourist destinations.
- Promotion of new technologies in order to improve patients' quality of life and free worldwide movement.
- Added-value tourist services in the VHP adhering countries.

## Further Suggestions

- To collaborate with international and national efforts in order to make possible interoperability between global countries in the medical tourism environment.
- To evaluate viability and sustainability of others business models based on the PHR supported technologies.
- New knowledge through PHR and EHR research.
- To establish international collaboration opportunities and to network contacts to work together improving and increasing PHR uses knowledge and to study its integration possibilities with EHR systems.

## Acknowledgements

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## References

[1] Traveler's Electronic Health Summary Template webpage. http://www.medinfo.org.tw/TET (Visited on February 2008).
[2] Health Level Seven (HL7) PHR functional model standard. http://www.hl7.org/Library/Committees/ehr/EHR%5FPHRSFM%5FR1%5FD1%5F2007NOV%20files%2Ezip (Visited on February 2008).
[3] MedKey webpage. http://www.medkey.com (Visited on February 2008).
[4] CapMed webpage. http://www.capmed.com (Visited on February 2008).
[5] HealthVault webpage. http://www.healthvault.com (Visited on February 2008).
[6] miVitals webpage. http://www.mivitals.com (Visited on February 2008).
[7] PatientsLikeMe webpage. http://www.patientslikeme.com (Visited on February 2008).
[8] Patient Opinion webpage. http://www.patientopinion.org.uk (Visited on February 2008).

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# ACCESS AND PRIVACY RIGHTS USING WEB SECURITY STANDARDS TO INCREASE PATIENT EMPOWERMENT

Filipa FALCÃO-REIS [a], Altamiro COSTA-PEREIRA [b,c], Manuel E. CORREIA [a]
[a] *Computer Science Department, Faculty of Science, University of Porto, Portugal*
[b] *CINTESIS - Center for research in health information Systems and technologies*
[c] *Biostatistics and Medical Informatics Department, Faculty of Medicine, University of Porto, Portugal*

**Abstract.** Electronic Health Record (EHR) systems are becoming more and more sophisticated and include nowadays numerous applications, which are not only accessed by medical professionals, but also by accounting and administrative personnel. This could represent a problem concerning basic rights such as privacy and confidentiality. The principles, guidelines and recommendations compiled by the OECD protection of privacy and trans-border flow of personal data are described and considered within health information system development. Granting access to an EHR should be dependent upon the owner of the record; the patient: he must be entitled to define who is allowed to access his EHRs, besides the access control scheme each health organization may have implemented. In this way, it's not only up to health professionals to decide who have access to what, but the patient himself. Implementing such a policy is walking towards patient empowerment which society should encourage and governments should promote. The paper then introduces a technical solution based on web security standards. This would give patients the ability to monitor and control which entities have access to their personal EHRs, thus empowering them with the knowledge of how much of his medical history is known and by whom. It is necessary to create standard data access protocols, mechanisms and policies to protect the privacy rights and furthermore, to enable patients, to automatically track the movement (flow) of their personal data and information in the context of health information systems. This solution must be functional and, above all, user-friendly and the interface should take in consideration some heuristics of usability in order to provide the user with the best tools. The current official standards on confidentiality and privacy in health care, currently being developed within the EU, are explained, in order to achieve a consensual idea of the guidelines that all member states should follow to transfer such principles into national laws. A perspective is given on the state of the art concerning web security standards, which can be used to easily engineer health information systems complying with the patient empowering goals. In conclusion health systems with the characteristics thus described are technically feasible and should be generally implemented and deployed.

**Keywords:** Privacy, Access Control, Electronic Health Records, Audit, Web Services, Patient Empowerment

## 1. Introduction

Our relationship with others is often affected by privacy matters. Privacy can be readily defined as our ability as an individual or as group to seclude ourselves or information about ourselves, allowing it to be revealed selectively and in a controlled way [1]. Although the boundaries and content of what is considered to be private are not and cannot be widely defined, it is generally considered to be a matter for the individual, as a member sensitive to the context of a society, integrated into its culture.

It is well known that current traditional and privacy mechanisms often fail to meet their purpose, i.e. to grant each individual the right to select and preserve the information that can and cannot be made public. The awareness of this right is often forgotten and society by itself does little to improve individual awareness of this basic right. There exists also a great obstacle to grant and empower each individual with his privacy rights. How can an individual contest access to his private information from a third party, when he is not aware of who wants it, for what purpose and for how long? This incapacity of easily tracking the flow of private data is producing a dangerous imbalance that could lead us towards a world, where some "big brothers" possess an ever increasing ability to "watch" us all the time and no one can watch what they are doing with the private information they end up collecting. Only by empowering each individual with the ability to know in a precise way who and when some entity accesses his private data can this situation start to be remedied and the balance of information distribution be reestablished.

The importance of creating data access protocols and mechanisms to protect our privacy rights and furthermore, to enable us to automatically track the data flows of our own personal information are growing fast. Privacy protection laws have been introduced in most of the "civilized" countries to prevent what are considered to be violations of very fundamental human rights, such as the unlawful storage of personal data, the storage of inaccurate personal data, or the abuse or unauthorized disclosure of such data [2]. Due to the development of automatic data processing, the OECD compiled guidelines [2] on the protection of privacy and trans-border flow of personal data. These guidelines should be considered as foundations for the research and design of access control system protocols for personal information that must also include provisioning for secure auditable actions and be also able to monitor changes to sensitive information.

Traditionally, medical records have been one of society's most valuable and tightly held personal records. The obligation to maintain patient confidentiality has always been widely regarded as a fundamental ethical responsibility of the medical professional [3].

With the continuing growth of the popularity of electronic health record systems that are not only designed to integrate electronic health records (EHRs), but also clinical decision support systems, data storage, prescription applications and administrative tools, the number of individuals that need to have access to this information as increased as well. The EHR systems are becoming more and more sophisticated and include nowadays numerous applications, which are not only accessed by medical professionals, but also by accounting and administrative personnel. So the access control lists, that ensure each individual user the access to a specific resource, have now very diverse categories of new entries and new users with new permissions to access different types of individual EHRs.

With so many different groups of people having the ability to access our own EHRs we argue that it is in our best interest to know who is accessing our medical records and for what purpose. Information is power and each individual should be entitled to the right to manage comprehensible access rights to his own EHRs.

## 2. Methods

A detailed search was carried out in order to gather bibliographic references containing various combinations of the following terms: privacy, electronic health records, access control, confidentiality and audit on Medline, Science Direct, Pub Med and Google Scholar. Papers were selected by title and abstract, as well as content relevance to the subject, and, whenever possible, the full text retrieved for further study.

## 3. Privacy

### *3.1. Privacy Principles*

In order to design reliable access control systems it is necessary to start by establishing some principles and guidelines that need to be taken into consideration in the early stages of system development. The main principles described in the guidelines compiled by OECD protection of privacy and trans-border flows of personal data should be regarded as mandatory minimum standards. Other measures could be added to further reinforce the protection of privacy and individual liberties:

- Data Quality Principle: There should be limits to the collection of personal data and any such data should be obtained by lawful and fair means and, where appropriate, with the knowledge or consent of the data subject [2].
- Purpose Specification Principle: Personal data should be relevant to the purposes for which they are to be used and, to the extent necessary for those purposes, should be accurate, complete and kept up-to-date [2].
- Use Limitation Principle: The purposes for which personal data are collected should be specified not later than at the time of data collection and the subsequent use limited to the fulfillment of those purposes or such others as are not incompatible with those purposes and as are specified on each occasion of change of purpose [2].
- Security Safeguards Principle: Personal data should not be disclosed, made available or otherwise used for purposes other than those specified in accordance with the use limitation principle except: with the consent of the data subject; or by the authority of law [2].
- Openness Principle: Personal data should be protected by reasonable security safeguards against such risks as loss or unauthorized access, destruction, use, modification or disclosure of data [2].
- Individual Participation Principle: There should be a general policy of openness about developments, practices and policies with respect to personal data. Means should be readily available of establishing the existence and

nature of personal data, and the main purposes of their use, as well as the identity and usual residence of the data controller [2].

- Accountability Principle: An individual should have the right: to obtain from a data controller, or otherwise, confirmation of whether or not the data controller has data relating to him; to have communicated to him, data relating to him (within a reasonable time; at a charge, if any, that is not excessive; in a reasonable manner; and in a form that is readily intelligible to him); to be given reasons if a request made is denied, and to be able to challenge such denial; and to challenge data relating to him and, if the challenge is successful to have the data erased, rectified, completed or amended [2].

The European Union also provides guidelines for the protection of personal data. The commission realized that divergent data protection legislation in the EU member states was preventing the free flow of data within the EU zone [4]. It was therefore decided to coordinate data protection regulation and to recommend a directive on the protection of personal data: Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data [4]. This Directive was progressively transposed in 1998 to each one of the member states internal law [5].

### *3.2. Privacy Audits*

Privacy audits can be defined as a systematic inspection and review of an entity data [6]. The purpose of such events is to establish whether personal information records are being maintained in accordance to the privacy principles previously stated and in accordance to the rule of law, i.e. to provide support for the principle of accountability and to detect security-policy violations. This is of a great importance if we aim to secure the enforcement of such principles.

At first, it may be something difficult to conceive, but to simplify this issue, we may start by creating a record map in order to perform privacy audits in a fast and efficient way as possible. The purpose of such a record map would be to enforce a general life model for each record. This operation should result in a flowchart that illustrate how and where each record is created, for what purpose and clearly indicates its path through the network [7].

The mapping of these records could, for instance, contain information related to the creation of the record, specific instances of how the record is used, the process or processes by which the record is updated and eventually deleted [7].

The audit consists on gathering information through a series of questions and then pursuing with its evaluation. Some of the evaluation questions can be [7]:

- What kind of data are you collecting?
- How the data is collected?
- For what purpose is the data collected?
- Are there any limits to gathering this data?
- Who owns the data?
- Who is the beneficiary?
- Who is using the data, for what purpose and how long will it be used?
- Where is it stored?

- Are there backups?
- Are there access logs?
- If so, where are the logs stored?
- Are the logs protected?
- What kind of security measures are used to protect the data?

Conducting privacy audits and collecting all of this information is one big step towards assuring secure privacy principles and individual liberties.

## 4. Electronic Medical Records

### *4.1. European Union Standards: Confidentiality and Privacy in Healthcare*

The European Union actively promotes the development of official standards on confidentiality and privacy in healthcare through the work of project EuroSOCAP (QRLT-2002-00771): an European Commission funded project (2003-2006) established to confront and attend to the challenges and pressures created within the healthcare sector between the information or knowledge-based society and the fundamental legal and ethical constraints of privacy and confidentiality that must rule the flow and dissemination of healthcare information [8].

These standards provide ethical guidance on confidentiality and privacy to healthcare professionals as well as recommendations to healthcare provider institutions on supporting frameworks for ethical best practices [8].

In this way it is possible to achieve a consensual idea of the guidelines that a member state should follow and implement such principles within their national laws.

### *4.2. Access Control*

Access control can be defined as the process of granting certain subjects access to a specific resource and denying access to others [7]. First of all, access control is a policy question. Policy is a reflection of business and security objectives that have been set in accordance with other organizational policies, the generally accepted practices of industrial and professional organizations, regulatory and legal requirements, and organizational goals [7].

In order to establish an access control scheme adequate for EHRs it is first necessary to determine who have access to what resource and in some situations what level of access should be granted by the system to some particular user. One could argue that the best model for implementing a scheme for accessing and controlling EHRs is a role-based access control (RBAC) model. The idea behind RBAC is to grant access to specific resources requested by a user according to his role within the organization [7]. His main distinguishable feature is that all access rights must be determined through the means of roles and roles can be hierarchical. This way it becomes easy to add and remove users' access rights to resources as he changes his function (role) within the organization. The role-based access schemes are established according to three rules: *role assignment* (where only users with assigned roles can interact with the system), *role authentication* (in order to access the system, the user must be authenticated before he can take on a role) and *action authorization* (users can

take actions after they are authenticated, these actions can be authorized or not depending on the role he's playing) [7].

Once this access control scheme has been established it is much easier to identify and manage the level of access that is granted to every user of the Electronic Health System. Eventually this point of granting access to an EHR could be developed and be made partly dependent on the wishes and policy actions of the patient that owns the record. So if someone expresses his wish to manage who should have access to his EHR, that wish should be granted based on his rights for privacy. This should be a priority policy: the patient that the EHR is about is entitled to define who is allowed to access his EHRs, besides the access control schemes each health organization has implemented. This way, it would not only be a special prerogative of health professionals to decide who have access to what, but the patient would also be entitled to play a part on those policy decisions, if he so wished. Only on justified cases of emergency, provided for by special roles, these personal access policies could be overridden. All these overriding roles must be widely audited and its actions fully justified.

Implementing such mechanisms and policies is walking towards patient empowerment. It is urgent to start to educate people in general about their privacy rights, and this must also include clinical data. In a globalized world people must be made aware of their rights and duties inside a much larger community. We are standing at a crossroads where the control of who owns and manages private information has yet to be decided and new tools must be given to the individual to help to reestablish the balance of power on who decides and directs the flow of private data.

### *4.3. Audit System for Electronic Health Systems*

There are several software systems designed and specially crafted to define, perform and analyze audit logs for health systems, some of which are widely deployed open source applications. One example is the Distributed Audit Service (XDAS). The XDAS specification defines a set of generic events of relevance at a global distributed system level, and a common portable audit record format to facilitate the merging and analysis of audit information from multiple components at the distributed system level [9].

### *4.4. A web service for enforcing accountability principle regarding EHRs*

Terms like "*patient empowerment*" [10] are very common these days. Indubitably, this is a reflection of our times and represents a noble goal that we should continue to pursue. Behind this concept is the general idea of granting patients the role of pro-active consumers that have the right to make their own choices as well as the ability to act and be responsible for them. Indeed who is better entitled to have access to his own EHRs than the patient himself? Shouldn't he have the right to know who accessed and modified his own EHRs, when and for what purpose? These privacy questions should be answered and presented to the individual the record is about, or at least, when the individual wishes to know about these issues he should be able to access some kind of service that can provide him with this information.

It is our belief that patient empowerment is something society should encourage and governments should promote. We present here a draft solution based on web services to start to provide some technical answer to these questions, i.e. to provide the

patient with information about which entities have accessed his EHRs thus providing him with the power to know how much of his medical history is known and by whom.

### *4.4.1. Basic Concepts*

The World Wide Web Consortium (W3C), which develops interoperable technologies (specifications, guidelines, software, and tools) to lead the Web to its full potential defines a web service as "a software system designed to support interoperable Machine to Machine interaction over a network" [11]. This interoperability is assured by using XML as the data representation layer for all web services protocols and technologies that are created [12]. A web service is frequently used as an application that presents a web API that can be accessed over the Internet. It can be develop based on several standards like SOAP, WSDL and UDDI [12].

Simple Object Access Protocol (SOAP) is a protocol that grants not only a standard packaging structure for transporting XML documents over a variety of standard Internet technologies, including SMTP, HTTP, and FTP, but also defines encoding and binding standards for programming non-XML RPC invocations in XML for transport. By having a standard transport mechanism, various clients and servers can easily be made interoperable [12].

Web Services Description Language (WSDL) is a XML-based language that provides a model for describing web services [11]. A WSDL document is independent from the language and platform used; it is composed by an abstract part, which describes exactly how the service messaging is defined and by another concrete part, related with implementation issues, which defines how and where the service is provided. We can define WSDL goals as: describing the services that are provided, presenting how the requests are processed by clients and service providers and pointing out the format of how the service sends information to a client. WSDL is generally used in combination with SOAP and XML.

Universal Description Discovery and Integration (UDDI) is a protocol for publishing and discovering metadata about web services that enables applications to automatically find them, either at design time or runtime [11]. It is designed to be interrogated by SOAP messages and to provide access to WSDL documents describing the protocol bindings and message formats required to interact with the web services listed in its directory [13].

In order to define access control policies within the context of web services the Organization for the Advancement of Structured Information Standards (OASIS) [13] developed the eXtensible Access Control Markup Language (XACML) based on XML standards. The request/response language expresses queries about whether a particular access should be allowed (requests) and portrays answers to those queries (responses).

### *4.4.2. Functionality*

The proposed web services provides patients with the ability to access audit records that track the access flow of their own EHRs. They can determine not only who accessed their EHR, but also which information, for how long and for what purpose. Other functionalities include events history and an alert system to help the patient focus his attention on potentially illegal access to his data. This system can mark entities or users that accessed the patient data and were defined by the patient to be suspicious or at least some attention should be given to them. Monthly reports as well as statistics

should appear as options in the service interface menu. Nevertheless all features implemented in this service should be customized by the patient, if he so desires.

### *4.4.3. Usability*

When regarding the implementation of such a service it is extremely important to pay attention to usability issues. In order to be easier for the user to implement his policies and to customize what he believes to be important, it's necessary to present him with not only a functional solution, but also, and this is very important, a practical solution. This practical solution must be as user-friendly as it can. It is of a great importance that the patient that is going to use this system finds it easy and accessible to use, in order to use it more often and also to find his needs and desires fulfilled.

The interface should take in consideration some heuristics [14] of usability in order to provide the user with best tools as possible:

- Visibility of system status: the system should always keep users informed about what is going on, through appropriate feedback within reasonable time [14].
- Match between system and the real world: the system should speak the users' language, with words, phrases and concepts familiar to the user, rather than system-oriented terms. Follow real-world conventions, making information appear in a natural and logical order [14].
- User control and freedom: users often choose system functions by mistake and will need a clearly marked "emergency exit" to leave the unwanted state without having to go through an extended dialogue. Support undo and redo [14].
- Consistency and standards: users should not have to wonder whether different words, situations, or actions mean the same thing. Follow platform conventions [14].
- Error prevention: even better than good error messages is a careful design which prevents a problem from occurring in the first place. Either eliminate error-prone conditions or check for them and present users with a confirmation option before they commit to the action [14].
- Recognition rather than recall: minimize the user's memory load by making objects, actions, and options visible. The user should not have to remember information from one part of the dialogue to another. Instructions for use of the system should be visible or easily retrievable whenever appropriate [14].
- Flexibility and efficiency of use: accelerators -- unseen by the novice user -- may often speed up the interaction for the expert user such that the system can cater to both inexperienced and experienced users. Allow users to tailor frequent actions [14].
- Aesthetic and minimalist design: dialogues should not contain information which is irrelevant or rarely needed. Every extra unit of information in a dialogue competes with the relevant units of information and diminishes their relative visibility [14].
- Help users recognize, diagnose, and recover from errors: error messages should be expressed in plain language (no codes), precisely indicate the problem, and constructively suggest a solution [14].

- Help and documentation: even though it is better if the system can be used without documentation, it may be necessary to provide help and documentation. Any such information should be easy to search, focused on the user's task, list concrete steps to be carried out, and not be too large [14].

#### *4.4.4. Implementation*

One way and arguably the best way to express policies based on RBAC schemes in the context of web applications is to use and apply eXtensible Access Control Markup Language (XACML) [15] profile specification. OASIS committee have approved in September 2004 a RB-XACML profile [16], which implements core and hierarchical components of ANSI standards such as roles and role hierarchies, permission-role assignment relation and user-role assignment relation [17]. However, version 2.0 of this specification does not support separation of duty.

The implementation of the privacy principles established by the OECD guidelines can be achieved with a XACML document expressing the relevant privacy policies [18]. The privacy audits could also be implemented and develop by XACML documents.

It is important to say that there is an open source implementation of the OASIS XACML standard, written in the Java™ programming language, developed by Sun Microsystems [19]. So the implementation and deployment of these policies can be easily integrated into any java based web application.

#### *4.4.5. Security*

One of the most important issues when attempt to implement a web service is security. Sometimes, security is forgotten and the applications as time goes by fail its purpose. In order to implement a web service we must pay attention to some issues regarding security, such as authentication, authorization, confidentiality, non-repudiation and integrity of data.

Authentication is how an identity is recognized. Authorization is the concept of allowing access to resources only to those who have permission to access them. The access control scheme is tightly connect with this concept [7].

Confidentiality ensures that only who is authorized to access specified resource is able to do so. It can be achieved through encryption of data.

Integrity ensures that a specific resource has not been interfered with, while non-repudiation provides evidence for the existence of a resource and ensures its contents cannot be disputed once sent [7].

In order to implement such concepts XACML offer a profile for use of the W3C XML-Signature Syntax and Processing Standard providing authentication and integrity protection [20]. This profile makes use of one appropriate format, the Security Assertion Markup Language (SAML).

SAML presents an XML-based framework for exchanging security-related information over networks, and thus over the Internet. Although SAML does not define newer mechanisms for authentication or authorization, it defines XML structures for representing information concerning authentication and authorization so that these structures can be understood by the recipient's security systems [21].

So by using this profile with XML digital signature mechanisms, we will be able to identify the data origin by identification and authentication of the message contents, as well as verify the message for data integrity and validating for accuracy and consistency [21].

## 5. Case study: illicit access to Electronic Health Records and how to prevent it

### *5.1. The problem: Sir Bobby Robson's EHRs viewed illicitly by NHS staff*

Rumors of an incident began last year in which the EHRs of former England Football Manager Sir Bobby Robson were viewed illicitly by members of the National Health System in the U.K., when he was scheduled for brain surgery in August 2006.

An internal hospital memo, leaked to the Chronicle newspaper in Newcastle, stated: "Over the last few weeks the ongoing security reports relating to the access by staff to the PAS (patient administration system) system and to the Casenote Tracker module has identified inappropriate access which has resulted in a formal disciplinary investigation and written warnings being issued to a number of trust staff who have accessed patients' information for no other reason than personal curiosity." [22]

The North Tees Primary Care Trust warned of a new security risk to the confidentiality of patient records under the NHS's National Programme for IT [NPfIT]. This warning consisted of a paper to trust board in March 2007 which referred to the Care Records Guarantee – which, under the NPfIT, gives an undertaking to patients that their confidential data will be protected from unauthorized access.

North Tees Primary Care Trust stated in the paper that: "A new security risk … has been identified as part of the Care Records Guarantee. This risk is around staff inappropriately accessing [a] patient's records who are not part of their care load. It was noted in an audit that a recent admission of a celebrity to a hospital had revealed over 50 staff viewing the patient record… Staff should only access records of patients with whom they have a legitimate relationship." [23]

### *5.2. The solution*

Audit systems play a very crucial role in detecting illicit access to EHRs in general. But if an audit system monitoring solely depends on people not directly involved with the information being wrongly accessed what naturally happens is what we have just related, private information is leaked and no one is responsible for the leakage. The real question is whether the staff responsible for hundreds of thousands of audits would be able to robustly police these accesses. A much more sensible solution would be to distribute and transfer this enormous auditing task into the hands of the truly interested party, the patient. This could take the form of an intelligent web based management system to support the analysis of audit trails. It would be a warning system like the one described previously and most importantly, it would enable each patient to have the capacity to monitor his own audit data.

## 6. Conclusion

The Article 12 of the Universal Declaration of Human Rights, established by the United Nations in 1948 (G.A. res. 217A (III), U.N. Doc A/810 at 71 ) states: "No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, not to attacks upon his honor and reputation. Everyone has the right to the protection of the law against such interference or attacks" [24].

It is a basic human right to be able to defend our own privacy and people must be given the tools to be able to secure for themselves this right. This is especially true for the sensitive information present in EHRs.

In general, patients are concerned that their EHRs fall into the hands of employers or government agencies without their permission and their knowledge. It should be a matter for the individual to decide whether he wants to share its personal information. A technical solution complying with the guidelines thus presented will most definitely help patients to become much more aware of this delicate health care and privacy issues.

## 7. References

[1] Diffie W., Hellman M.E. – Privacy and authentication: An introduction to cryptography. IEEE. 1979 March; 67(3):397-427.
[2] OECD – Organization for Economic Co-operation and Development. OECD Guidelines on the Protection of Privacy and Trans-border Flows of Personal.
[3] Feldman D., Novack D., Gracely E. - Effects of Managed Care on Physician-Patient Relationships, Quality of Care, and the Ethical Practice of Medicine. Archives of Internal Medicine. 1998;158:1626-1632.
[4] European Commission – Data Protection: Directive 95/46/EC on the protection of personal data.
[5] European Commission – Justice and Home Affairs: Data Protection.
[6] Wolley S. – Data Security and Privacy Audits adding value to the organization.
[7] Windley P, Digital Identity. O'Reilly. 2005.
[8] EuroSOCAP – European Standards on Confidentiality and Privacy in Healthcare.
[9] The Open Group. Distributed Audit Service (XDAS) Base. 1997. Accessed in February 2008.
[10] Segal L, The importance of patient empowerment in health system reform. Health Policy, Volume 44, Issue 1, Pages 31-44.
[11] Ceremi E, Web Services Essentials. O'Reilly. 2002.
[12] Chappel D, Jewell T, Java Web Services. O'Reilly. 2002.
[13] OASIS – Organization for the Advancement of Structured Information Standards.
[14] Nielsen J, How to conduct a Heuristic Evaluation. 1994.
[15] OASIS - eXtensible Access Control Markup Language (XACML).
[16] OASIS – Core and hierarchical role based access control (RBAC) profile of XACML v2.0.
[17] Crampton J, DIMACS Workshop on Secure Web Services and e-Commerce – XACML and Role-Based Access Control.
[18] OASIS – Privacy Policy Profile of XACML 2.0.
[19] Sun's XACML implementation. Available at: http://sunxacml.sourceforge.net/. Accessed in February 2008.
[20] OASIS - XML Digital Signature profile of XACML v2.0.
[21] Steel C, Nagappan R, Lai R, Core Security Patterns: Best Practices and Strategies for J2EE™, Web Services, and Identity Management. Prentice Hall PTR / Sun Micros. 2005.
[22] ComputerWeekly.com – Sir Bobby Robson's EHRs viewed illicitly by NHS staff. Available at: http://www.computerweekly.com/blogs/tony_collins/2007/09/bobby-robsons-medical-records-1.html. Accessed in February 2008.
[23] ComputerWeekly.com – NpfIT security warning after NHS staff view celebrity record. Available at: http://www.computerweekly.com/blogs/tony_collins/2007/09/npfit-security-warning-after-n.html. Access in February 2008.
[24] Garfinkel S, The database nation: the death of privacy in the 21st century. O'Reilly. 2000.

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# Immunizations: The First Step in a Personal Health Record to Empower Patients

Mr. Michael L. POPOVICH[1], MS, Dr. Jeffery J. ARAMINI[2], PhD, MSc, DVM, Mr. Michael GARCIA[3], MS
*Scientific Technologies Corporation*

**Abstract**. Despite the promise of better health care through information-centric patient empowerment, little progress has been made. The issue is not that the data do not exist in a useable form, nor that technologies are lacking that would enable access to this information. There are two primary challenges standing in the way of patient empowerment: (1) in the private sector there is no proven revenue model for providing this access and (2) in the public sector the standard argument is confidentiality of information. The lack of a priority by either private or public health providers to empower individuals will lead to these initiatives being consumer driven. Access to immunization records through health informatics and supporting compunetics presents an easy-win opportunity to significantly empower individuals with their own health information.

Scientific Technologies Corporation (STC) has been implementing and supporting immunization registries in North America for over fifteen years. As the leading expert in this area, STC has developed a process for achieving successful large-scale access to personal immunization records with minimal investment. As a first step to empower individuals with on-line access to their immunization records, the STC approach leverages the technical frameworks established for health insurance and 3rd party payer environments linking to statewide immunization information systems. The individual is provided access to their records through their insurer's health portal. This is populated through electronic exports of member immunization records as retrieved from state or provincial registries that contain provider-supplied patient records, allowing individuals to utilize these hosted services or download their provider administered records into their personal health record.

Individuals have the ability to review their immunization and their family immunization histories. They have the ability to know when an immunization is due, where vaccines are available, and which vaccines minimize risks to disease. For the emerging industry of on-line personal health records, a patient's immunization record will be the single most important factor to demonstrate success for patient empowerment. It will create a roadmap to support the inclusion of other medical information.

**Keywords.** Immunization record, personal health record (PHR), compunetics, patient empowerment, health informatics.

[1] CEO, STC, 4400 E. Broadway, Suite 705, Tucson, Arizona 85711 USA, +1 520.202.3333, Michael_Popovich@stchome.com
[2] Public/Animal Health Epidemiologist, Director of Canadian Operations, STC – Canada, 8153 Side Road 15, RR3 Fergus, Ontario N1M 2W4, Canada, +1 519.766.3800, Jeff_Aramini@stc-canada.com
[3] Vice President/COO, STC, 8370 E. Via de Ventura, Scottsdale, Arizona 85258, +1 602.241.1502, Mike_Garcia@stchome.com

## 1. Background

Day in and day out there are press releases from health care providers, vendors, and departments of health stressing the value of individuals assuming a greater role in managing their health care. The economic cost impacts of a proactive health program are well known and encouraging individuals to be a catalyst to accelerate proactively is a win for all. As such, individuals require health information, they need to know what it means, and they need to know how to use it. They need to be able to make decisions, ask questions, and stay informed.

The provider community understands the value of historical and real time information to support health care decisions for their patients. They understand the need to share information as patients receive services from a variety of health care professionals. Providers address this need through information sharing. Whereas the expanding electronic medical record (EMR) environment is facilitating an infrastructure to support the provider community, the emerging personal health record (PHR) will facilitate the use of the individual's medical records to support management of their specific care. The question will become how to populate a PHR.

It is difficult for individuals to contribute to their own health care team if they do not have ready access to their own personal health information. Patients empowered through information are more likely to understand the risks and benefits of certain activities (e.g., immunizations, disease screening) and are more likely to be proactive in their own health care. Health informatics together with medical compunetics provide the tools for information to significantly shape an individual's personal health care environment. Accessible information will facilitate informed decision making and contribution by ALL members of the health care team: physicians, other health care partners (e.g., pharmacists, specialists), and most importantly, the patient. Better informed health care teams should translate into better personal care, providing a long term economic benefit for societies by preventing disease, mitigating direct health care costs, and promoting a healthy and more productive workforce.

Despite the promise of better health care through information-centric patient empowerment, little progress has been made. And although progress is being made to implement EMRs, significant barriers exist to enable wide-spread direct patient electronic access to this information. This paper presents an approach to achieve immediate real gains in patient empowerment by facilitating electronic access to a key component of an individual's personal health record: their immunization data.

## 2. The Universal Significance and Need for Personal Immunization Records

| | |
|---|---|
| Access to immunization records through health informatics and decision support through health compunetics presents an easy | win opportunity to significantly empower individuals. Whether it is a yellow fever, malaria, hepatitis, measles, or new vaccines for emerging infectious diseases or chronic illnesses, immunizations are universally available. Understanding what is required and when and ensuring a family is fully protected is complex. Figures 1, 2, and 3 summarize immunizations currently recommended for children aged 0 – 6 and 7 – 18, and adults in the US. [1] |

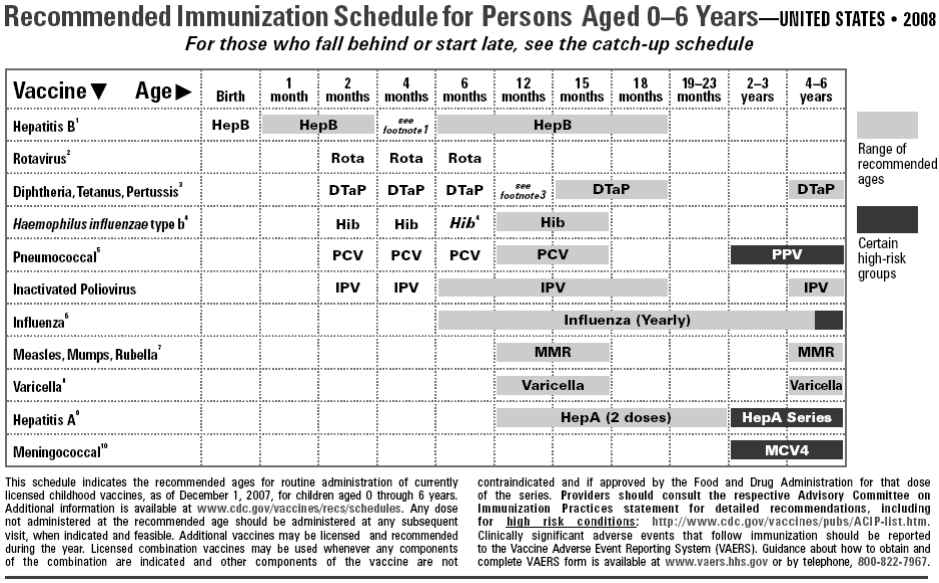


**Figure 1.** Recommended immunization schedule for persons aged 0 – 6 years, United States, 2008.

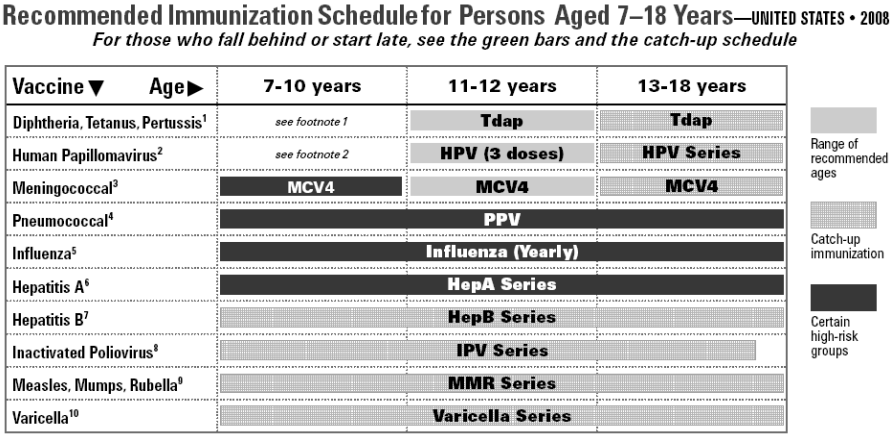


**Figure 2.** Recommended immunization schedule for persons aged 7 – 18 years, United States, 2008.

Immunizations are recommended and provided to new babies, adolescents, and the elderly. From Hepatitis B given at birth, to adult boosters including those for tetanus, pertussis, and influenza and new vaccines for pneumonia and shingles, the need for immunizations persists throughout an individual's entire life. As such, a complete

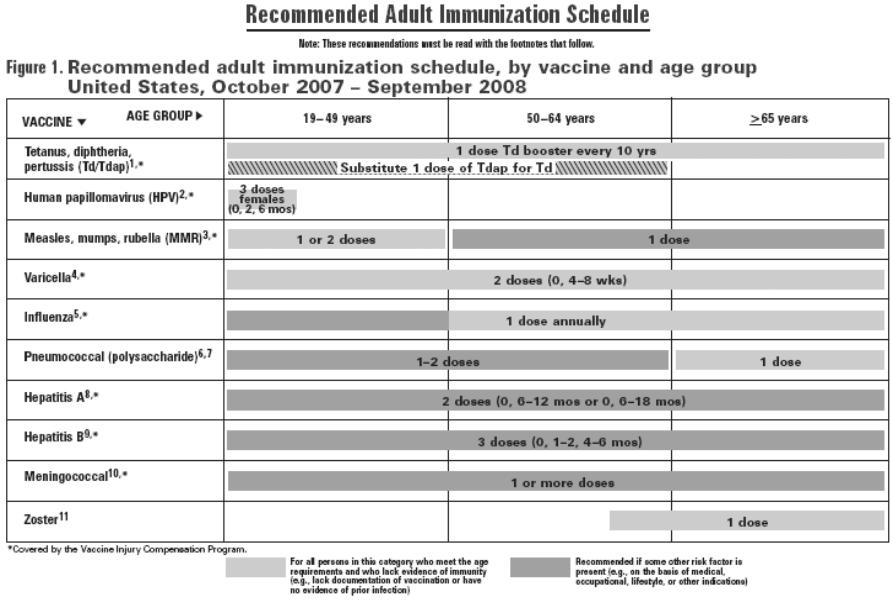


**Figure 3.** Recommended adult immunization schedule, United States, October 2007 – September 2008.

immunization history should be a required component of a person's health record. The value of health compunetics is that this record can then be evaluated to determine what risks an individual has to vaccine-preventable diseases. Having an immunization history and tools to determine risks will empower individuals to be proactive.

## 3. Immunization Recordkeeping and Patient Empowerment: the Gaps

An individual's immunization record needs to be complete to provide an accurate assessment of risk. Immunization records are retained by individual providers, but rarely consolidated into a single medical record across the patient's health care lifecycle. Each vaccine that is provided by a health care professional results in a paper or electronic record, retained in the custody of the primary provider. When individuals move and/or change physicians, records will exist in multiple locations.

With the advent of electronic health records, individual immunization data may eventually be consolidated under the patient's current provider but these records are not likely to be as mobile as the patient. Patients can request from past providers copies of their families' immunization records but often the effort required to do this is seen as prohibitive, and for the provider such requests add administrative costs to search, retrieve, and provide this information. [2]

The first challenge is where or how to generate a single complete immunization record for an individual. Ultimately, there are three locations where complete records are found. The most likely is in a home paper record kept by conscientious individuals themselves. The second location is with 3rd party organizations that ultimately pay for the services. And finally, at least in North America, records may end up in a consolidated regional immunization registry that is used by public health organizations to support vaccine-preventable disease programs. For example, in the U.S., forty-nine of the fifty state health departments have implemented statewide immunization registries, [3] and in Canada all provinces will be expected to implement immunization registries in the next few years. It is the state and provincial immunization registries where the combined patient records can be found and they will become the trusted source of this information. However, no public access is offered for this information.

Personal immunization records must be easily accessible. Individuals do not have access to their own immunizations records even if they exist in an electronic database. Without easy access it is difficult for an individual to review their own and their family's immunization status. The primary challenge standing in the way of patient empowerment is the lack of priority by immunization data custodians to open these registries to the public. Data confidentiality is the key barrier. As such, there is a source for a combined patient record but no mechanism for sharing this with the public. The challenge then becomes the second gap to overcome: how to make available this resource.

Driven by good public health practice, economics, and national oversight, 3rd party insurers, both private and government, have active immunization program efforts to encourage their provider networks to increase immunization coverage rates of their patient populations. [4] Providers send immunization record information to their payee networks for reimbursement and to state health departments to maintain their immunization registries.

The National Committee for Quality Assurance (NCQA) [5] is a US federal agency that evaluates quality of care. All insurance companies provide reports annually on the level of their services. A key measurable criterion is immunization coverage. This is determined from the immunizations histories of patients who are members of the insurance plan. A significant effort is made by insurance companies to gather this data, often through costly on-site provider visits involving the review of a random subset of patient records. With the implementation of statewide immunization registries at the health departments, insurance companies now can receive electronic copies of all their member records if desired. The key to patient access and thus a successful patient empowerment project is through the insurance companies.

## 4. Immunization Recordkeeping and Patient Empowerment: Arizona Case Study

Since 1994, the State of Arizona has had in operation a statewide immunization system. Data are collected directly from providers through electronic information exchange and

through direct data entry. Currently this registry has over 18,400 users, including providers, school nurses, and state health professionals. The system maintains immunization records (over 31 million to date) for approximately 3.2 million individuals, most of whom are under the age of 18. [6] The state total population is over six million and there are new initiatives underway to include adult immunizations in the system.

Immunization data is utilized by providers to determine the next appropriate vaccination, by public health officials to support immunization programs that minimize the impact of vaccine-preventable diseases on the populations at risk, and by 3rd party insurers for their quality of care programs as well as pay for performance. Individuals do not have access to their personal immunization records in this closed system.

Given that the immunization registry infrastructure is in place to collect, store, and retrieve this information, the next step is to implement a patient access view into these records. This is achievable by establishing the following criteria for patient access:

- The data are secure and only available to the individual.
- No identification or location data is provided or can be viewed, but only immunization histories.
- No user access is available to the immunization record source network (i.e., providers or state health departments).
- No special software or equipment is required to access information.
- Additional immunization tools are available to support an individual's ability to use this information in the management of their own health care, to include forecasting next due date, identification of missing vaccines, and risk assessments.

With these criteria a secure web-based patient access health portal is recommended. A portal that leverages existing security and record access tools limits access to information to the specific individual that is authenticated through password protection and a portal that provides the most complete on-line record available with standardized tools to support immunization record assessment for patient decision management.

Figures 4, 5, 6 and 7 illustrate a proposed solution. This solution leverages the health insurance/3rd party payer environments by providing access to records through the health portal of an individual's current insurer. When a member connects to their insurance company's health portal, an option exists to access their immunization records which would be retained as a copy from a source data repository such as a state immunization system. Family records would also be available. The insurance company becomes the repository of the record which is also used to support their vaccine-preventable programs and their quality of care programs.

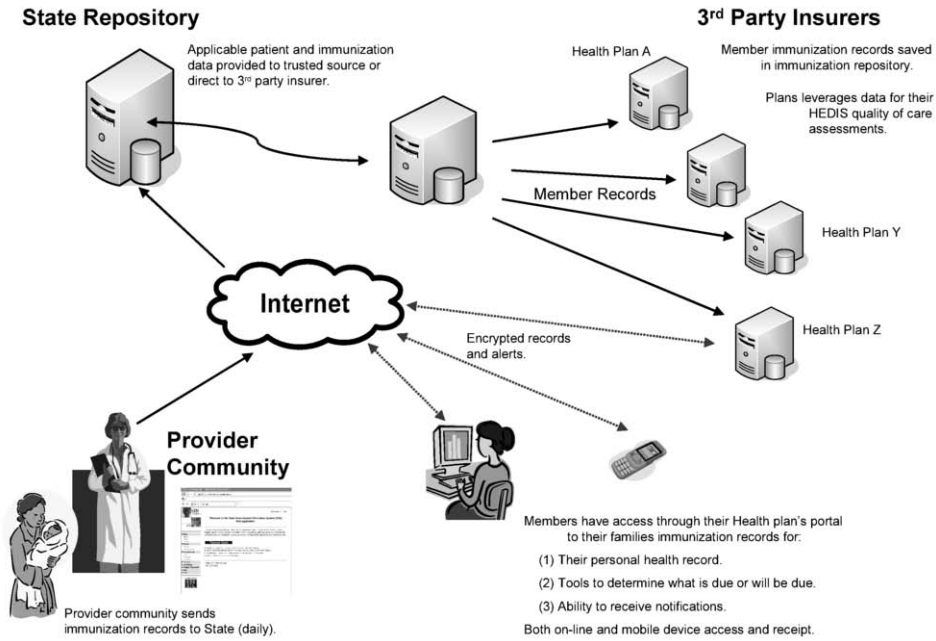


**Figure 4.** Access to personal immunization records through insurer's health portal.


**Figure 5.** Example health portal with link to "My Immunizations."

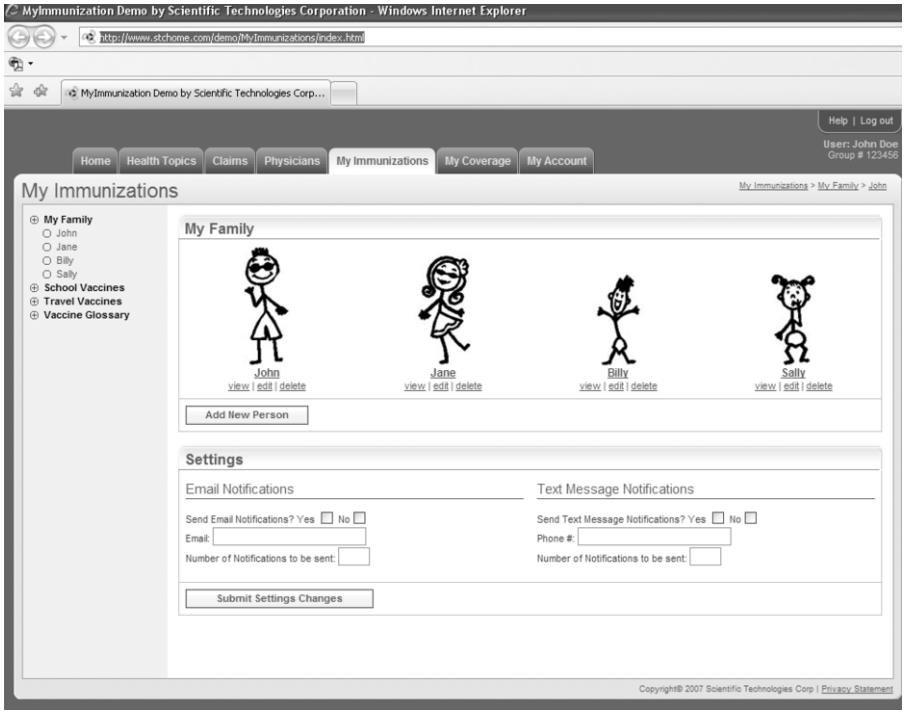


**Figure 6.** Example immunization management solution.

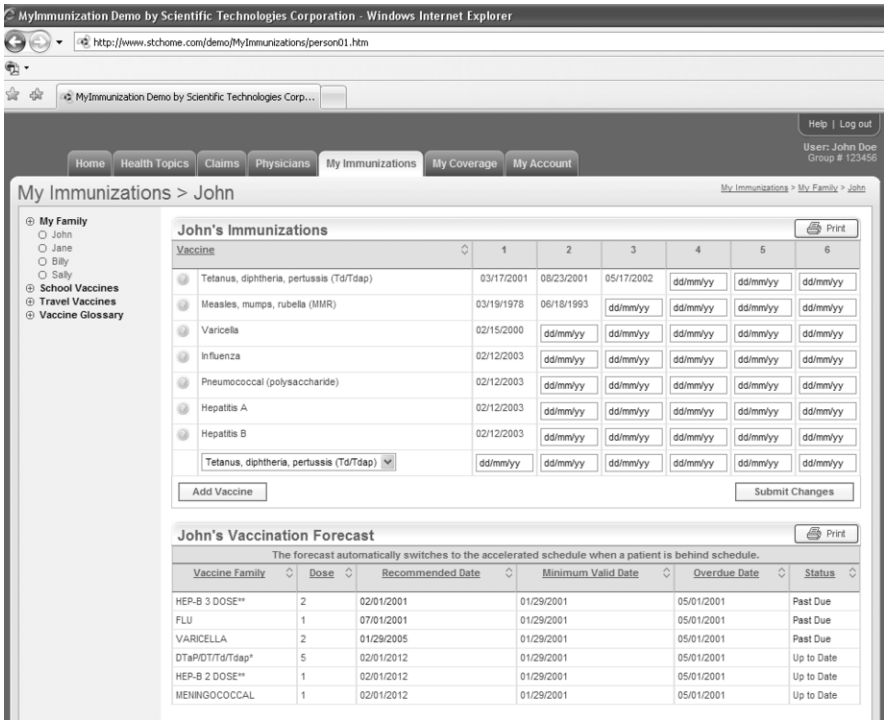


**Figure 7.** Example immunization management solution.

This solution would include processes to access the patient historical records and advice on immunizations due and date required, recommended optional vaccinations, and additional immunization-related information as appropriate. Members would not need to access this health portal to be proactive in maintaining their family immunizations as the system would automatically, through an electronic notification feature, email, or text message, send a reminder that an immunization is due.

The solution as envisioned does not require a complex technical component. The most difficult element will likely be the establishment of memorandums of agreement between participating organizations. Technically, the steps in implementing the solution are as follows:

1. Establish secure electronic links from a state immunization system to the Insurer's patient immunization database for data exchange.
2. Initially populate the Insurer's database with existing member data retained in the state system. For new members or patient updates, leverage the electronic query capability through an HL7 message request to retrieve updated or new records on demand or similarly through semi-monthly batch queries.
3. Implement a member's access sign-on into the Insurer's e-health portal and establish appropriate security and administrative protocols.
4. As members request, provide immunization histories to include:
    - Listing of personal and family member immunization records;
    - Listing of due dates and recommended immunizations based on patient age and immunization history.
    - Provide the capability to allow the member to forecast in the future what immunization is due based on a date entered.
    - Provide members with the ability to enroll for automated alerts when immunizations are due, flu shots are available, etc.
    - Provide access to general information of interest that the Insurer would like to promote (e.g., adolescent vaccines, influenza vaccination programs).

In addition, as the PHR becomes more prevalent it would be possible to allow the member to download their immunization records into their PHR. As members leave this Insurer, through the eligibility rules patient records would be purged.

## 5. Conclusions

Although the solution described in this paper is within the current technical environments of all parties, personal electronic immunization health records have yet to be implemented in North America. It is simply a matter of time until individuals will have electronic access to their immunization records. This will be driven not through government or provider initiatives, but from consumers demanding access to their own personal health data or through the economics of health care.

Access to personal immunization data will have a number of direct benefits, including empowering individuals to improve their health and reducing the personal and societal impacts of disease. Furthermore, health care providers and insurers will experience a significant economic return on the limited investment required to implement this type of solution.

Although there are ongoing debates relating to the potential costs and benefits associated with providing consumers access to their entire medical records, access to personal immunization records is a universally accepted concept. Enabling access to personal immunization records provides a low-cost, low-risk, first step towards more broad-based access to personal health information. The economic and health benefits to individuals and communities associated with patient empowerment through information access will be profound. It will perhaps be the single most important health initiative to be implemented in the next decade.

## References

[1] US Centers of Disease Prevention, 2008, http://www.cdc.gov/vaccines/recs/schedules
[2] 2003 cost studies have shown economic impacts of $5/chart to retrieve medical files.
[3] American Immunization Registry Association, http://www.immregistries.org/public.php/ImmRegs
[4] In the US individuals can choose to not receive required immunizations and opt out of these programs.
[5] http://www.ncqa.org/
[6] Arizona State Immunization Program, 2008 Statistical Summary.

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*Medical and Care Compunetics 5*
*L. Bos et al. (Eds.)*
*IOS Press, 2008*



# Intelligent Device Management in the Selfcare Marketplace

Christos G. Biniaris [a,1] and Andrew J. Marsh [b]
[a] *VMW Solutions Ltd., UK*
[b] *University of Westminster, UK*

**Abstract.** Over the last ten years the Internet has emerged as a key infrastructure for service innovation, enabling IP (Internet Protocol) to become the wide area network communication protocol of choice. The natural result of this choice is that service providers and their customers are looking for ways to optimise costs by migrating existing services and applications onto IP as well. A good example is the medical industry, which is transitioning to Internet-based communications as the field of telemedicine broadens to preventative and self healthcare. However, technology is changing quickly and consumers face an array of choices to satisfy their healthcare needs with numerous devices from different vendors. Seamless healthcare device networking can play a major role in automating and safeguarding the process of collecting and transferring medical data, remote patient monitoring and reducing costs through remote equipment monitoring. In this scope, we describe an approach augmenting the Session Initiation Protocol (SIP) with healthcare services in order to form a framework for efficient collection and storage of measurements, aiming to address the issues of the lack of a standardised data interface for consumer healthcare technologies (including hardware and protocols) and the lack of a standardised format for self-collected healthcare data (including the storage medium). In this framework, measurements can be seamlessly collected and stored as XML notes located virtually anywhere, such as the user's home or mobile device. Additionally, these notes can be accessed locally or remotely by doctors and specialists. Also, we discuss how this approach supports user mobility by proxying and redirecting requests to the user's current location and how it can remove the complexity of using consumer healthcare technologies from different vendors connected to different devices and the opportunities for Independent Software Vendors to develop additional services.

**Keywords**. Consumer Healthcare Services, Self-care, Session Initiation Protocol

## Introduction

Consumer healthcare technologies are driving opportunities to serve patients in new ways and in new settings, through the combination of the advances in communication and networking technologies (e.g. smart houses, personal communications devices broadband connectivity, digital cameras & video, wireless, etc.) with modern healthcare approaches (e.g. remote patient monitoring, personal health records, electronic medical records, e-prescribing, e-disease management, e-clinical trials,

[1] Corresponding Author: Christos G. Biniaris, VMW Solutions Ltd., 9 Northlands Road, Whitenap, Romsey, Hampshire S051 5RU, United Kingdom; Email: chris.biniaris@vmwsolutions.com

telehealth/telemedicine, sensors, call centres, customer relationship management technologies, doctor/patient email, virtual physician visits, etc.).

Forrester Research Inc.'s [1] has coined the term "Healthcare Unbound" to encompass the trends towards self-care, mobile care, and home care. More specifically, Forrester Research describes Healthcare Unbound as "technology in, on and around the body that frees care from formal institutions." By 2015, Forrester projects that 60 percent of all patients discharged after a lengthy hospitalisation, 40 percent of all chronically ill, and 12 percent of all seniors, will adopt healthcare unbound technologies and services. Some of the main benefits flowing from the convergence of consumer and healthcare technologies include: Gathering vital sign data from patients remotely, providing information to patients anywhere and anytime, automating information flow among patients, healthcare providers, and payers, reducing costs and improving quality and keeping people in their own homes (rather than in hospitals or nursing homes)

In the enlightening report, "Consumer Healthcare Electronics: Consumers are Ready, Willing and Able", Accenture [2] found that consumers are eager to play an active role in managing their health and embracing emerging home healthcare technologies. According Forrester, the healthcare unbound market will experience slow but steady growths through 2008, and then surge to $34 billion by 2015, following the entrance of third-party payers, like the Centres for Medicare & Medicaid Services.

Additionally, the health conscious represents a growing market. More and more people are turning to self-diagnosis rather than waiting for an appointment with their doctor. Figures have revealed that in 2003 £55 million was spent on carrying out Do-It-Yourself (DIY) health tests ranging from the basic pregnancy tests to male fertility tests. Market Research company Mintel states that Five years prior, the figure was only £40 million, a growth of some 32% since 1998. In additional, Mintel reports six in ten Britons have at least one self-diagnostic product at home, with the simple thermometer being the most popular.

Forrester's forecast predicts adoption of three types of healthcare unbound solutions: activities of daily living support and elder monitoring, chronic care maintenance, and acute post-hospitalisation care management. Each segment will experience unique growth trends during the following three phases:

- The Era of Self-Pay: 2004-2008: Initial healthcare unbound growth will be fuelled by consumers who see a value in paying for healthcare unbound out of pocket, namely affluent chronic illness sufferers and caretakers for sick or aging family members.
- The Era of Validation: 2008-2010: Growth will accelerate as healthcare vendors entice third-party payers with studies that prove valuable long-term cost savings from healthcare unbound investments.
- The Era of Third-Party Payment: 2010 And Beyond: Solid evidence of healthcare unbound's ability to improve healthcare efficiencies will spur third-party reimbursement, sparking rapid adoption of healthcare unbound solutions.

Taking into account the above, it is obvious that there is a need for infrastructures that will support seamless healthcare device networking, as well as automated and user

transparent data collection, transfer, storage and presentation. This paper attempts to meet all these goals by extending existing approaches combining SIP with the provision of healthcare services [3]. In particular, the current work suggests an approach that combines the networking capabilities of SIP with a modular architecture in order to provide flexible and efficient services related to data acquisition, transmission storage and presentation. In this context, initially an overview of SIP is presented, followed by a detailed description illustrating the elements of the suggested architecture. Subsequently, an example scenario is presented and finally some concluding remarks are given.

## 1. Overview of Session Initiation Protocol (SIP)

Converged networks have come a long way since the 1990's. New applications like Instant Messaging, Unified Communications, and IP Telephony have accelerated the adoption and the deployment of converged voice and data services in the enterprise. Since its inception in the late 1990's, SIP (Session Initiation Protocol) [4]-[6] has revolutionized the way people communicate with each other using converged services. SIP provides the framework for delivering voice, video, data and wireless services seamlessly and transparently over a common network. SIP is an RFC standard (RFC 3261) from the Internet Engineering Task Force (IETF), the body responsible for administering and developing the mechanisms that comprise the Internet. SIP is a signalling protocol used for establishing sessions in an IP network. Being a request-response protocol that closely resembles two other Internet protocols, HTTP and SMTP (the protocols that power the World Wide Web and email), SIP sits comfortably alongside Internet applications.

A SIP session could be a simple two-way telephone call or it could be a collaborative multi-media conference session. The ability to establish these sessions means that a host of innovative services become possible, such as voice-enriched e-commerce, web page click-to-dial, Instant Messaging with buddy lists, and Independent Software Vendor (ISV) application services. SIP invitations used to create sessions carry session descriptions which allow participants to agree on a set of compatible media types.

Taking into account the above, it can be seen that using SIP, standard communication services like telephony can become web applications easily integrated into other Internet services. In fact, over the last couple of years, the Voice over IP (VoIP) community has adopted SIP as its protocol of choice for signalling.

SIP also supports user mobility, by proxying and redirecting requests to the user's current location. Users can register their current location and can receive SIP calls wherever they are. Furthermore, the changes needed to support device mobility are minor [7], a fact that is related mainly to the simplistic philosophy SIP is built around: specify only what you need to specify. Having been developed purely as a mechanism to establish sessions, SIP does not know about the details of a session, it just initiates, terminates and modifies sessions. This simplicity means that SIP scales, it is extensible, and it sits comfortably in different architectures and deployment scenarios.

SIP is still evolving and being extended as technology matures and SIP products are socialized in the marketplace. Its main Components consist of:

- SIP User Agent Client (UAC) - A client application that initiates SIP requests.
- SIP User Agent Server (UAS) - A server application that receives a SIP request and returns a response on behalf of the user.
- SIP Proxy Server - The proxy server is an intermediate device that receives SIP requests from a client and then forwards the requests on the client's behalf. Proxy servers receive SIP messages and forward them to the next SIP server in the network. Proxy servers can provide functions such as authentication, authorization, network access control, routing, reliable request re-transmission, and security.
- SIP Registrar - Processes requests from UACs for registration of their current location. Registrar servers are often co-located with a redirect or proxy server.
- SIP Media Server - Houses the SIP application that is being requested. Could be voice, video or data.

## 2. The suggested architecture

This work suggests a SIP-based architecture that integrates with other internet services, enabling collaboration with one or more participants. When used with an IP structure, this architecture enables rich seamless healthcare communications with numerous multi-vendor devices and media. Healthcare sessions between any numbers of enabled endpoints can be set up, including consumer healthcare devices, PC's, Personal Digital Assistant's (PDAs) and cell phones. Participants could be using end devices from any number of different vendors. Since the architecture is based on SIP, it supports session descriptions that allow participants to potentially agree on a set of compatible media types and services. It also supports user mobility by proxying and redirecting requests to the user's current location. An overview of the architecture is depicted in Figure 1.

The basic elements of the architecture are the clients and the network servers. The client software is implemented in, or close to, consumer healthcare devices and controls a SIP connection to a network server which routes SIP requests to the appropriate service. Consumer healthcare devices effectively become enabled endpoints under the control of the relevant services. The components of the architecture are explained in further in the following sections.

### *2.1. The Client*

The client can be a lightweight software module, suitable for embedding in end-user devices such as mobile handsets or PDAs. Alternatively, it can be incorporated within other desktop applications. A client consists of a local connection manager and a SIP user agent. The local connection manager handles the data connection to the consumer healthcare devices and the SIP user agent handles the IP connection to the system's

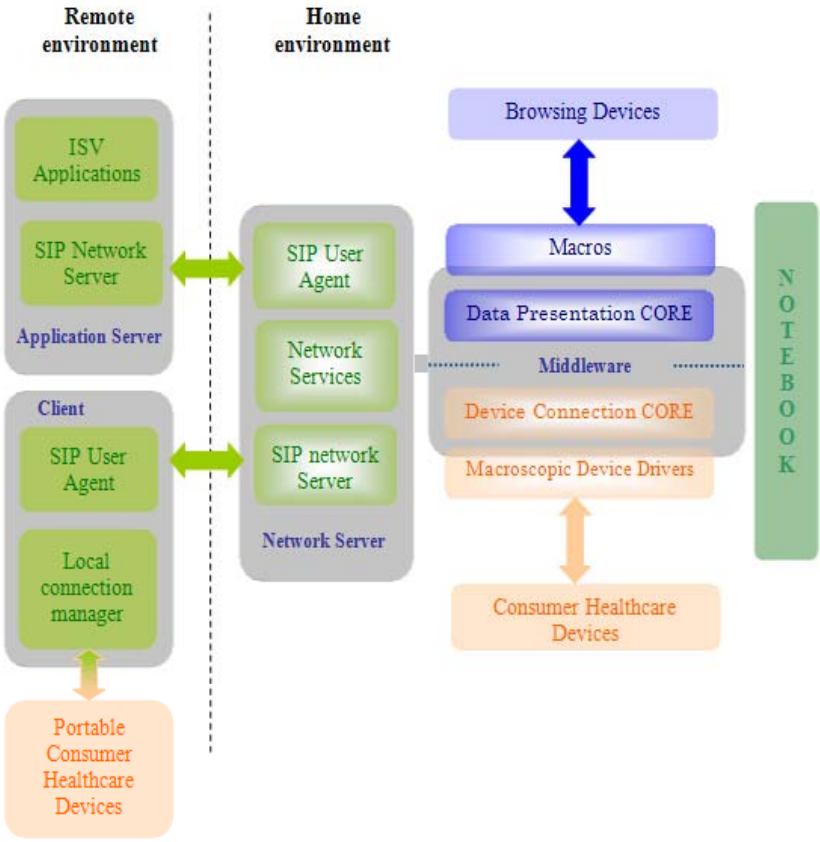


**Figure 1.** The suggested architecture

services. When involving a mobile device in such a communication scenario, three main parameters have to be taken into consideration namely, the limited processing power, the storage capabilities and the interface software, required to communicate with the consumer healthcare device. The client architecture is depicted in Figure 2.

Considering a scenario where a mobile device is connected, using Bluetooth [8], to a portable consumer healthcare device, such as an ambulatory blood pressure monitor, the measurement from the blood pressure monitor is sent via Bluetooth to the mobile device in proprietary raw data format and then redirected, without the need of any specific consumer healthcare interface software, over IP through the network server to an appropriate service which interprets the proprietary raw data format and performs checking, analysis and storage. By using this approach, the consumer healthcare device becomes an endpoint to this service. This procedure removes the software interface requirements imposed on the mobile device. In order to avoid data loss, the client also

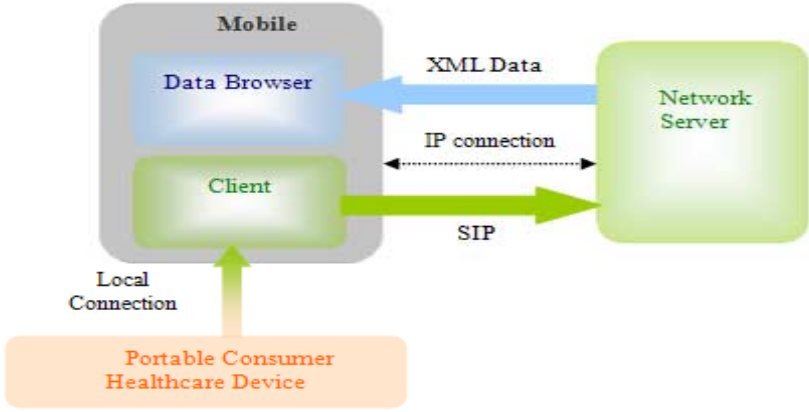


**Figure 2.** The client architecture

supports data caching in case of link failure. In which case, the cached data can be transferred upon the reestablishment of the connection.

In order to view the measurement, the mobile device uses a data browser, which receives structured data originating from the service, in standard XML format, and displays it on the screen of the mobile device.

Considering another scenario where a healthcare device, for example, a blood pressure monitor is located in a public place such as an office or fitness center. Since the device is an endpoint, measurement data is then sent, over IP, to the user's network server, which could be located in the user's home, and then the measured values, for


**Figure 3.** The Client sending data (left) and the Browser displaying XML data (right) in a Nokia 6630 Mobile Smartphone

example, returned to the user's mobile handset and/or stored on the users home PC for later viewing. By means of this type of clients, the complexity of using consumer healthcare technologies from different vendors connected to varying devices is removed.

### *2.2. The Network Server*

In addition to the SIP network server and SIP user agents which support the IP connectivity, the network server also includes solutions for NAT traversal. As part of the network server, the services are the key components that enable flexibility and adaptability regarding:

- The connection and integration of consumer healthcare devices from any number of different vendors, as well as of new methods to process the data
- The incorporation of new methods and environments to view and analyse the data

In order to achieve both these goals, the services are divided into two parts, namely the "Device Connection" services, and the "Data Presentation" services.

#### *2.2.1. "Device Connection" services*

The "Device Connection" services comprise of two elements, the "Device Connection Core" core and the "Macroscopic Devices Drivers". The "Device Connection Core" includes the coordination functionality related to the communication and interpretation of proprietary consumer healthcare device data protocols, implemented through the "Macroscopic Devices Drivers". The core also facilitates open APIs to support the development of components, data analysis and storage. The main functionality offered by these APIs can be thus summarized as follows:

- On-the-fly alarm checking of measurement data and on-demand trend analysis with historic data
- Interpretation of the propriety data protocols for each consumer healthcare device.
- Connectivity protocols for example Bluetooth (Serial Port Profile), RS-232 and IP.
- Data logging, SNOMED CT encoding and 128 bit encryption within XML structures, called notebooks.

The aforementioned architecture gives the opportunity for Independent Software Vendors to expand and tailor the functionality of the Core according to their needs through the implementation of customized software modules.

#### *2.2.2. "Data Presentation" services*

The "Data Presentation" services similarly comprise of two elements, namely the "Data Presentation Core" and the "Macros". The Core includes the basic functionality related

to the presentation of the user's historic data, depending on the viewing platform and data presentation requirements. Software components will support the Core to reformat the information to be displayed in a format customised for the viewing platform (e.g. iTV, PC, PDA). This functionality is implemented with components called Macros. Each Macro describes specific methods and functions regarding the transformation of data format. The Core facilitates four open APIs to support Independent Software Vendors development of interfaces targeting PC, PDA, mobile and iTV platforms. The main functionality offered by these APIs can be thus summarized as follows:

- Transformation of stored data to a desirable format defined by an Independent Software Vendor.
- Customised screen presentation methods, according to the specifications of the displaying device.
- Decoding and decryption of the stored data as well as data interpretation mechanisms (e.g. XML parsing).

### *2.3. Application Server*

Designed to support Independent Software Vendor (ISV) applications (see Figure 4), the application server consists of two elements namely the SIP network server and the ISV application. By using the suggested architecture, the ISV application has a seamless connection to the user's data files. Customers can build systems using relevant enabled devices and collaborative applications from multiple vendors. This

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      </MEASUREMENT>
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```

**Figure 4**. XML structure of the Notebook

allows them to select the combination of price and features that best suit them, the software that works best in their environments and give individual end users the devices they are most comfortable with. In addition, enabled endpoints and network servers can be added to existing IP infrastructures without effecting existing IP-based applications.

### *2.4. Notebook*

For interoperability, ease-of-use and portability of the stored data, the approach of encrypted data containers, called notebooks has been adopted. Each notebook is an encrypted XML [9] document where the user's data is stored. The stored data is encoded according to the SNOMED CT [10] and encrypted, using an Asymmetric Encryption Scheme, according to a user's PIN. The data is stored in the notebook in a hierarchical format under XML nodes called "iNotes". Each iNote contains information regarding one or more measured values taken at the same reading by a specific healthcare device. For example, a Blood Pressure monitoring device can measure Systolic Blood Pressure, Diastolic Blood Pressure and Pulse rate at the same reading. Since these three measurements are taken together they are included in the same iNote. An iNote can therefore be regarded as a healthcare event or observation. Such a structure of stored data, not only provides a straightforward and efficient way of accessing the data, but also provides the means of building more advanced models of knowledge management mechanisms.

## 3. An Example Scenario

The architecture's components can be integrated with existing IP-based components, such as VoIP, to provide a seamless healthcare service (Figure 5). For example, the doctor initiates a SIP request to her patient advising him to take his blood pressure measurement (1). The doctor does not need to know the location of the patient or by what means (phone, SMS, email) to contact him. These issues are all handled by the patient's Network Server. Since the patient is at work a flash message arrives at his mobile phone (2). If he was at home for example, the message could be displayed on his TV. The patient uses the office Blood Pressure Monitoring Device and his enabled mobile phone to take his measurement (3a). His Client routes the measurement to his Network Server (3b) where it is processed by his relevant service. The measurement is stored in his notebook (4), sent back to his phone in XML format, where it is displayed on his mobile phone screen (5a) and forwarded to the his doctor ISV application (5b).

## 4. Conclusions

Healthcare services on the Internet are becoming prevalent. However, interoperability across institutional boundaries is often an issue when designing such a service, even more so when considering preventative and self-care services targeting end users in

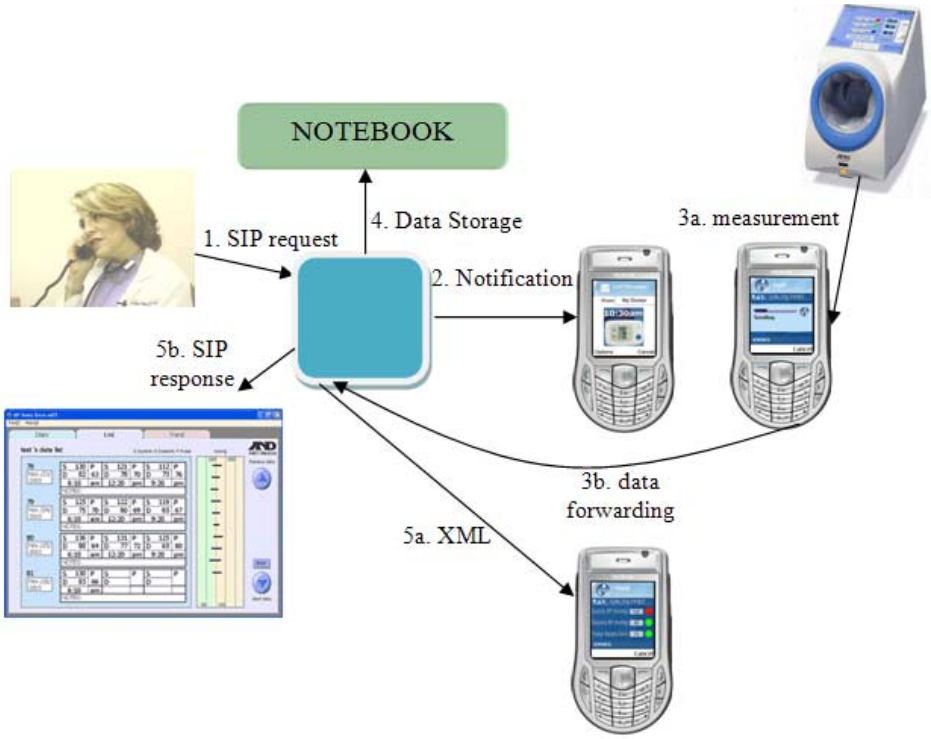


**Figure 5.** An example scenario

their daily environments. The suggested architecture provides a flexible and robust solution which not only addresses this problem, but uses existing consumer healthcare technologies as well as providing enhancements to it. Individual end users can use whichever devices they are most comfortable with and healthcare professionals can use the software that works best in their environment. This strategy will bring new capabilities to the users by opening up the application development process to new players. At the same time, the open nature of the architecture will enable enterprises and users to buy equipment, devices, consumer healthcare technologies and software from more suppliers, providing them more flexibility.

## References

[1] www.forrester.com
[2] www.accenture.com
[3] K. Arabshian and H. Schulzrinne, A SIP-based Medical Event Monitoring System, 5th International Workshop on Enterprise Networking and Computing in Healthcare Industry (Healthcom 2003), Santa Monica, CA ( 2003).
[4] M. Handley, H. Schulzrinne, E. Schooler, J. Rosenberg, SIP: session initiation protocol, Request for Comments 2543, Internet Engineering Task Force, Available http://www.ietf.org/rfc/rfc2543.txt, (1999)

[5] J. Rosenberg, H. Schulzrinne, G. Camarillo, A. R. Johnston, J. Peterson, R. Sparks, M. Handley, E. Schooler, SIP: session initiation protocol, Internet Engineering Task Force, RFC 3261, Available http://www.rfc-editor.org/rfc/rfc3261.txt (2002).
[6] A. B. Roach, Session initiation protocol (sip)-specific event notification, Internet Engineering Task Force, RFC 3265, Available: http://www.rfc-editor.org/rfc/rfc3265.txt (2002).
[7] E.Wedlund, H. Schulzrinne, Mobility support using SIP, Second ACM/IEEE International Conference on Wireless and Mobile Multimedia (WoWMoM'99), Seattle, Washington (1999).
[8] https://www.bluetooth.org/
[9] http://www.w3.org/XML/
[10] http://www.snomed.org/snomedct/index.html

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# Ethical Issues of Brain Functional Imaging: Reading your Mind

Irene S. Karanasiou [a,1], Christos G. Biniaris [b] and Andrew J. Marsh [c]
[a] *School of Electrical & Computer Eng., National Technical Univ. of Athens, Greece*
[b] *VMW Solutions Ltd., UK*
[c] *University of Westminster, UK*

**Abstract.** Neuroimaging practice and research are overviewed in this paper through an ethics lens. The main ethical implications in biomedical research concerning functional brain imaging are discussed with the focus on issues related to imaging of personal information and privacy. Specific norms and guidelines will be eventually formed in the future under the umbrella of the new discipline of Neuroethics.

**Keywords.** Functional Brain Imaging, Neuroethics, brain reading, privacy

## Introduction

Biological and medical research have extremely and spectacularly advanced the past decades and, combined with the pertinent scientific and technological progress, have produced significant evolution in the health field. Amongst others, one of the most salient outcomes is the ability to have a close view inside the human brain from the outside using biomedical imaging techniques.

This progress is of major significance, since the brain is indeed the most important and special organ system in the human body; it is the most complex organ in terms of structure and functionality, characterized by the multitasking nature of its individual structures, while in parallel it is very special since it is the seat of the mind.

Traditional modalities are constantly enhanced by sophisticated post-processing techniques, whereas emerging technologies provide new insights in anatomical, functional, cellular, and molecular level. Medical imaging is used primarily as a diagnostic tool in the clinical practice, but is equally applied nowadays in biomedical research. While in clinical practice the focus of all medical decisions and suggestions is to benefit the current patient, the purpose of data collected during biomedical research are further post-analysed in order to possibly infer results that may have a positive impact on the improvement of healthcare of currently unknown beneficiaries in the future.

Consequently, the conduct of biomedical research involving human participants raises a significant number of ethical, legal and moral issues related to a number of fundamental values as the individual, the family, health, human rights and dignity,

[1] Corresponding Author: Irene S. Karanasiou, Microwave and Fiber Optics Laboratory, School of Electrical and Computer Engineering, National Technical University of Athens, 9 Iroon Polytechneiou, Zografos GR-15780, Athens, Greece; Email: ikaran@esd.ece.ntua.gr

body integrity, autonomy, and privacy. In this context, a new discipline has emerged from the field of Bioethics, derived from the progress in neuroscience, which is rapidly increasing our knowledge of neural correlates of the mind, exploiting the advances in biomedical brain functional imaging. This development raises ethical problems, whose importance is likely to surpass even the implications of modern genetics. Neuroimaging practice through an ethics lens is termed as Neuroethics.

In this paper, we provide a brief overview of the neuroimaging technologies most commonly used in the biomedical neuroimaging research context and then discuss a variety of ethical issues arising from the use of these technologies, focusing mainly on those related to potential brain reading and privacy. Neuroethics encompasses a broad and varied set of bioethical implications. Explicit discussion and education about the moral issues involved amongst researchers, practitioners, and moral educators may eventually lead to specific normative guidelines in the future.

## 1. Biomedical Imaging and Ethics

### *1.1. Biomedical Imaging Techniques*

Body medical imaging is realised with the use of special sensors and devices that detect the radiation which is transmitted, emitted or scattered by the body and of the appropriate embedded electronics which interpret this information into medical images of the whole body or parts of it. Recording techniques that do not primarily result in medical images but carry mapping information of the measured data also constitute body imaging methods. Standard methodologies using X-rays, gamma rays, radiofrequency and ultrasound waves have become an integral part of clinical practice, but others with operation principles based on special properties of visible and infrared light, microwaves, terahertz rays and electric and magnetic fields are also being explored. Nevertheless, new imaging methodologies in combination with bioinformatics, biotechnology, nanotechnology and the technological advancement of computational hardware and software, may lead to novel clinical imaging approaches [1].

The imaging modalities are mainly divided in two self-explanatory categories; structural and functional. The former are used to quantitatively determine the three dimensional structure of tissue, whereas the latter can monitor its functional state. These imagers are not only intended for clinical use, but equally used in biomedical research.

Biomedical imaging research involves the participation of human beings who serve as sources of data. It should be noted that in the use of these personal data lies the disparity of the two approaches, clinical and research. In clinical practice the ultimate focus of all medical decisions and suggestions which comprise and lead to the relevant diagnostic and/or therapeutic interventions is solely to benefit the current patient [2]. Conversely, the purpose of systematically collecting data elicited during biomedical research is to further post-analyse it in order to possibly infer results that could be generalised and may have a positive impact on the improvement of healthcare of currently unknown beneficiaries in the future [3].

Consequently, the conduct of biomedical research involving human participants raises a number of ethical, legal and moral issues that have concerned philosophers, lawyers, policy makers, clergy, scientists, and clinicians for many years [4], with a

variety of ethical concerns related to a number of fundamental values as individual, the family, health, human rights and dignity, body integrity, autonomy, and privacy [5], [6].

### *1.2. Ethical Implications and their management*

All of the aforementioned ethical issues have formed the past two to three decades a new field of study, a broad discipline which tackles the ethical implications of biomedical research and the applications of that research, especially in medicine. Specific legal provisions regarding these ethical concerns pertaining to matters of participant safety, informed consent, and confidentiality have been formed into a complex regulatory apparatus in the USA [5], [7]. Respectively, the European Council's aim in the field of Bioethics is to establish principles and legal standards for the protection of the individual's dignity and fundamental human rights, implicated in the application of classic, standard medical procedures and new medical techniques, enabling at the same time freedom of research [8]. In summary, the most prominent ethical implications of the participation of human beings in medical research are to serve beneficence, prevent or alleviate non-maleficence, preserve fidelity between investigator and participant, ensure personal dignity and autonomy and to protect the privacy of personal information [9].

One of the topics of particular interest among bioethicists is the handling of human tissue specimens that may be used for present, or stored for future, research purposes [5], [10] or the stem cell research and their future and further use. Accordingly and most importantly, in what way is the bioethics debate affected when the centre of attention becomes the most significant part of the human existence but the least tangible one, the human brain and mind? How should data related to brain activity imaging be managed?

The significant advances in the field of functional neuroimaging and neuroscience in conjunction with the unique attributes of the brain as an organ system and its centrality to our concept of our own humanity, raise numerous pressing ethical questions that are expressed through a new emerging discipline, "Neuroethics". This field will become increasingly important as science, technology and medicine advance opening up new perspectives to diagnosis and treatment, generating expectations for improvements in the mental health and well-being of people throughout the world, while challenging our traditional understanding of human existence.

## 2. Functional Neuroimaging

With the view to exhibit the various aspects of the ethical implications of functional neuroimaging, it is initially important to fully understand the type of signals that are measured with functional modalities as well as their limitations. Therefore, a brief overview of the most common brain functional imaging techniques is presented in this section.

Functional neuroimaging is broadly defined as those techniques used to provide measures of brain activity [11], [12]. Functional modalities measure an aspect of brain function, often with a view to understanding the relationship between activity in certain brain areas and specific mental functions; they are being used, in other words, to map localized cognitive processing and to examine brain plasticity. The activation of specific brain regions is related to increased local brain activity and/or increased

regional cerebral blood flow, blood volume, blood oxygen content, and changes in tissue metabolite concentration [12].

Common functional imaging methodologies include mainly Positron emission tomography (PET), single photon emission computed tomography (SPECT), functional MRI (fMRI) and functional near infrared spectroscopic imaging (fNIRS). Also, two other techniques more directly linked to the electrical activity of neurons than is fMRI, electroencephalography (EEG) and magnetoencephalography (MEG) are widely used in research. Neither EEG nor MEG is true 3D imaging modalities, but comprise information that with the appropriate post-processing provide 3D brain mapping of the recorded data.

### *2.1. Functional Magnetic Resonance Imaging (fMRI)*

Functional MRI (fMRI) is a non invasive neuroimaging method based on MRI which doesn't require ionizing radiation and detects changes on regional levels of oxygenated blood [13].

The most frequently used technique is known as "blood oxygenation level dependent" (BOLD) contrast, which exploits small magnetization differences between oxygenated and deoxygenated blood [14]. Thus, fMRI measures blood flow and is an indirect measure of brain activity [11]. This method provides information on neural activity that is complementary to contributions from MR spectroscopy and PET [1], [15], [16].

### *2.2. Positron Emission Tomography (PET)*

PET is based on the detection of photons arising from the decay of injected radiotracers (i.e., radiolabeled molecules) [17]. With the ability to image various radiotracers and their distribution within the brain, it is possible to follow molecular interactions and pathways [18]. PET can thus follow the brain's response to stimuli and has long enjoyed a prominent role in neurologic research. SPECT is similar to PET but is more readily available and considerably less expensive [19]. This modality measures changes in blood flow and receptor activity using different radiotracers while the data are used to create images of slices of brain on different planes [17].

### *2.3. Optical Methods*

Optical methods, such as near infrared spectroscopy (NIRS), provide another non-invasive measure of regional brain activity based on the absorption of different wavelengths of light as it passes through the head [20]. The two dominant chromophores for the NIR wavelength range are two biologically relevant markers for brain activity (oxyhemoglobin (HbO2) and deoxyhemoglobin (HbR)). Thus, NIR wavelengths pass relatively easily through tissue, and their absorption can provide information relevant to brain function. Moreover, by recording data from several wavelengths simultaneously, one can measure also other tissue chromophores. Since brain activity is associated with changes in optical properties of brain tissue, non-invasive optical measurements during brain activation can assess blood chromophore oxygenation state, and two types of changes in light scattering reflecting either membrane potential (fast signal) or cell swelling (slow signal), respectively. After early studies employing single-site near-infrared spectroscopy, first near-infrared imaging

devices are being applied successfully for low-resolution functional brain imaging [20], [21].

### *2.4. A short comparison*

Functional MRI (fMRI) is faster and less invasive than positron tomography (PET), and although slower than electroencephalography (EEG), it has much better spatial resolution (e.g. [22]). fMRI has also spatial resolution, temporal resolution, and signal-to-noise ratio that are superior to that of positron emission tomography (PET). Nevertheless, fMRI is very sensitive to motion. Relevant correction algorithms are implemented during post-processing which are not entirely always satisfactory, generating even in some cases false signal assessments [14], [23].

PET has also several disadvantages, such as exposure to radiation (the dosage is comparable to CT) and the substantial expense of the technology compared to other types of imaging [24] – [26].

Studies currently focus also at a combined concurrent implementation of various modalities, such as EEG recordings and functional magnetic resonance imaging (fMRI) during event-related experimental procedures, near-infrared spectroscopy and EEG recordings aiming at achieving sufficient temporal and spatial resolution to clarify the functional connectivity of neural processes, provided that the method combination represent the same neural networks (e.g. [27]).

In the light of the above, it is obvious that all the technological tools and methodologies for the diagnosis of various functional variations and alterations in the brain caused by stroke, lesion, and neurological disease or under normal functional activity are currently available in biomedical research. It is even becoming possible to associate specific brain areas with certain cognitive processes and psychological characteristics. Despite the rich promise for mental healthcare advancement that these developments hold, they also raise thorny ethical questions: Does science have the permission to invade human mind by analyzing thoughts and emotions? How could the findings be misused or misinterpreted? Under what conditions does brain imaging become like mind reading posing potentially the ultimate threat to personal privacy?

## 3. Neuroethics and imaging of personal information: do you want a piece of my mind?

### *3.1. Reading the mind and protection of privacy*

Recently, numerous articles on the new neuroethical questions implicated in research in neuroimaging and neuroscience have been reported in literature (e.g. [28]-[30]) and meetings and symposia have also appeared on the subject [31].

The first specific references to Neuroethics and neuroethical issues in the literature were made almost two decades ago, while the first world conference on Neuroethics was held in 2002 [32]-[35]. The term Neuroethics, introducing a new discipline which is a subcategory of Bioethics, was coined initially by William Safire [36] and was further given additional definitions by other researchers [37], [38]. The term Neuroethics has currently been adopted to refer generally to ethical issues in the technological advances of neuroscience [39]-[41].

At a minimum, the same basic ethical standards should be applied to brain research as to any other area of clinical work: 1) the safety of new research and treatment methods, 2) the rationing of promising new therapies with fairness and equity of access to the benefits of the research outcome and 3) the protection of the vulnerable population [42], [43].

However, new neuroethical issues have emerged and are unique to neuroimaging research because of the particularity of this field of research. They are strongly related to the study of the most important and complicated organ of the human body, the organ of the mind and consciousness, the locus of our sense of selfhood and human existence, the brain. The main two advances from which emanate the most important neuroethical considerations are one hand, the ability to detect brain function in humans with sufficient spatial and temporal resolution to combine it with neuropsychologically meaningful fluctuations of activity and on the other, the ability to intervene in the brain with chemical or anatomical selectivity that may induce specific functional changes.

The brain comprises billions of neurons and its various activated parts interconnect and interoperate. Individual parts of the brain do not act separately alone and appear to be involved in more than one function. Moreover, according to most people's understanding, mind is actually the brain and this close relation, even coincidence of the two concepts is so central to our human existence that the relationship between brain and mind always exists in any explanation of what is widely conceptualized as normal or abnormal brain function. Hence, any intervention in our brains would not only cause potential physical disability, but would also impact our cognition, emotion, or even our personalities [40], [42].

Researchers are beginning to identify brain processes that are related to experiences and concepts by using neuroimaging devices to elucidate the areas of the brain that are activated when people react to ideas, provocative issues, feelings or stimuli. Studies show for instance that pessimism, persistence and empathy even unconscious racial attitudes and sexual preferences seem to have neuroimaging correlates [42]. In this sense, our progressing knowledge of mind-brain relationship is likely to affect our definitions of competence, mental health and illness, life and death.

At the same time, those processes become increasingly accessible to specific intervening techniques. Damage to the brain can change personality and behaviour and these changes are often expressed by non conformal social conduct. Interventions in the brain therefore have different ethical implications than interventions in other organs while any intervention, however small or precise, is unlikely to have a single consequence [44]. In addition, the ethical questions of neuroscience are more urgent, as neural interventions are currently more easily accomplished than genetic interventions [43].

Moreover, brain imaging may also provide information about the biological foundations of our mental traits, an application that is in many ways analogous to genetic information. Like genotyping, "brainotyping" can reveal information about mental health vulnerabilities and predilection for violent crime [45]. It should be noted that due to overgeneralization of findings in the genetics of intelligence, possible genetic predisposition to greater or lesser intelligence was often attributed to specific racial or ethnic groups. Neurogenetic findings of intelligence, levels of aggressiveness or violence interpreted in a similar way would certainly lead in misuse of data and the creation of false stereotypes or stigmatization individuals or groups [43].

Hence, the most obvious and significant ethical concern of neuroimaging research involves privacy. By revealing characteristics of personal identity through 'reading' of

the relevant neural correlates, problems of individual rights on privacy, non-interference and inviolability are caused. For instance, employers or the government have a strong interest in knowing the abilities, personality, reliability and other mental contents of certain people. This raises the question of whether, when, and how to ensure the privacy of our own minds. If we consider the ethical issues implicated by the implementation of The Schengen rules for sharing intelligence and information about EU citizens, we can imagine the extend of these ethical considerations when it comes to human minds and intimate thoughts. If existing and emerging technologies can indeed reveal the neural correlates of our innermost thoughts then our sense of the privacy and confidentiality of our own thought processes may also be threatened [45]. Individuals must be protected from brain reading, its interpretation and further use of the elicited data. Questions concerning underlying concepts of humans and cognitive profiling should be actively dealt with by interdisciplinary and public debate [44].

All of the above issues reveal the need of norms that would determine the researcher's obligations for informing their research participants about the way they make decisions. These decisions are mainly related to the social and cultural consequences of enabling humans to manipulate their own minds, the impact that neuroscience will have on our self-understanding and our concept of humans and the way information about our biologic dispositions to addictive behaviours and special traits are used for specific purposes. It should be noted that all the data collected through this type of research could be further managed towards a broader scientific scope. For example, there will be increasing interest in the possibility of data mining in banks of neuroimages as it is discussed in the field of stem cell research. Thus, clinicians and biomedical researchers should consider anticipating future research uses and request from participants consent for further usage of their data in future research projects.

The age of information and science progress has possibly produced the age of 'technology of consciousness' [44]. Science and technology are once again requested to develop a moral consensus framework this time in the neuroimaging research field. Of course, current functional neuroimaging or genotyping cannot determine personality and intelligence with any precision. Brain imaging is at best a rough measure of personality in its current state but this does not certainly imply that it will not develop into a significantly more reliable "brainotyping" tool in the coming years [45]. This research assumes that by peering into the brain, science can begin to answer all of the aforementioned questions about behaviour, personality and human existence; but underlying this assumption is a broader one; namely, that the brain and the mind are essentially one and the same and this relation still remains rather elusive [46].

### *3.2. Other Important questions in Neuroethics*

Other important ethical implications of biomedical neuroimaging research which are also closely linked to individual privacy can be summarized as follows.

#### *Informed consent of cognitively compromised and psychiatrically challenged individuals*

Are people that are cognitively compromised or impaired capable of fully understanding their participation in experimental neuroimaging research and its consequences? Many clinicians and investigators believe that neuroimaging holds great

promise, especially in the areas of behavioral and cognitive disorders. But which are the management guidelines of the data elicited from research involving the participation of the psychiatrically ill? Moreover, potential benefits of applying neuroimaging, psychopharmacology and neurotechnology to mentally ill persons have to be carefully weighed against their potential harm [44].

*Infants, children as participants in neuroimaging experiments*

Two main ethical issues are implicated in neuroimaging research with children: on one hand the ethical aspects of developmental neuroimaging and on the other privacy and confidentiality of children's health information. How are children privacy rights protected when participating in biomedical research? How are potential stigmatization issues managed in this milieu since functional neuroimaging tests may be predictive in nature or may be diagnostic for behavioral, cognitive, or mental disorders? The need of developing detailed guidelines with respect to pediatric neuroimaging and especially of disabled children becomes imperative. Also, best practices for handling unanticipated and incidental findings for mitigating, inappropriate diagnoses and prognoses, for assessing risk versus benefit and whether to include young children in pharmaceutical trials should be developed (e.g. [12]-[14], [17], [14], [31], [34]).

*Limits of Manipulation of Normal Brain Functions*

Under which circumstances is psychopharmacological enhancement of attention, memory or mood considered the only treatment and in which cases the use of technologies such as psychosurgery, deep-brain stimulation or brain implants is justified? So, what are the boundaries about pharmacological, technological and genetic fears of behaviour modifications which are capable of affecting the individual's sense of privacy, autonomy and identity [45].

*Beginning and End of Consciousness and Definition of Brain Death*

When does the human existence begin, when an embryo becomes sentient and when is a dement or vegetative individual no more a person?

*Interpretation of data and limitations of neuroimaging modalities*

Are brain scans viewed as accurate and objective as they in fact are? Concerns about the risks of various neuroimaging modalities and the potential for misinterpretation of imaging results are emerged. Many layers of post-processing techniques separate imaged brain activity from the psychological inferences deriving from it. There is a danger that the public and authorities will ignore these complexities and treat brain images as a kind of indisputable truth [45].

## 4. Conclusions

Since the ancient years, the comprehension of operation of human brain and its relation to the behavior and the nature of the human mind were subject of philosophical discussions and quests. It is only in the past few centuries that significant advancement was made in both basic and clinical neuroscience towards the understanding of the

subtle mechanisms and complex relations of the structure and function of the human brain.

The current decade may be remembered in the future for the progress of neuroscience beyond the categories of basic and clinical, into a host of new research applications. Rapidly expanding knowledge in the functional brain imaging research field offers not only the promise of dramatic cures and amelioration of mental health, but also a profound understanding of the brain's functionality. With the scope to define the boundaries of the new discipline Neuroethics that will deal with the emerging ethical implications of neuroimaging research, the relevant ethical and policy challenges posed by our growing knowledge need to be identified.

Many aspects of the new discipline should be covered with the cooperation and interaction between neuroscientists, scholars in biomedical ethics and the humanities, lawyers, and public policy makers. Basically, clinical brain research is subject to the same ethical guidelines and regulations as any other field of research with humans. These include regulations governing conflicts of interest, confidentiality, data and safety monitoring of clinical trials, institutional review boards and informed consent. However, with exceptional capabilities of reading the human mind in health and disease, our ethical responsibilities have reached a broad new level.

It is evident that the general bioethics rules are not adequate for this kind of research. Most new discoveries about the brain are both subtle and complex. From the measurement of mental processes with functional neuroimaging to their manipulation with drugs, the new capabilities of neuroscience raise unprecedented ethical, social and legal issues in relation to the human nature and the brain. Nevertheless, 'reductionist' interpretations of neuroscientific results challenge notions of free will and personality rights which are essential for culture and society. Thus, interpreting the new findings appropriately for practical and policy use is essential and requires a deep understanding of the strengths and weaknesses of the relevant experiments and of the limitations that surround the scientific findings and theories derived from them.

Beyond the neuroimaging ethical topics raised so far, many other avenues in neuroethics require exploration, discussion, and debate. Since our responsibility to the pursuit of new knowledge is a historical mandate and part of the human nature, these issues must be identified and addressed in an open dialogue to prevent potentially considering the benefit of functional imaging research contentious in the future and ensure that society will fully benefit from the neuroscience revolution now in progress.

## References

[1] A. B. Wolbarst, W. R. Hendee, Evolving and Experimental Technologies in Medical Imaging, Radiology 238 (2006), 16–39.
[2] P. Sankar, Communication and miscommunication in informed consent to research, Medical Anthropology Quarterly 18 (2004), 429–446.
[3] Code of Federal Regulations, Part 46.102(d).
[4] The ethics and regulation of research with human subjects, C. H. Coleman CH, J. A. Menikoff, J. A. Goldner, et al. Newark: Matthew Bender Co, 2005.
[5] M B Kapp, Ethical and legal issues in research involving human subjects: do you want a piece of me?, Journal of Clinical Pathology 59 (2006), 335-339.
[6] http://www.coe.int/t/e/legal_affairs/legal_co-operation/bioethics/
[7] The birth of bioethics, A. R. Jonsen. New York: Oxford University Press,1998.
[8] http://www.coe.int/t/e/legal_affairs/legal_co-operation/bioethics/

[9] The patient as partner: a theory of human experimentation ethics, R. M. Veatch. Bloomington: Indiana University Press, 1987.
[10] R. Hakimian, D. Korn, Ownership and use of tissue specimens for research, Journal of American Medical Association 292 (2004), 2500-2505.
[11] M. D'Esposito, Functional neuroimaging of cognition. Seminars in Neurology 20 (2000), 487–498.
[12] J. Downie, J. Marshall, Pediatric Neuroimaging Ethics, Cambridge Quarterly of Healthcare Ethics 16 (2007), 147–160.
[13] Y. Frank, S. G. Pavlakis, Brain imaging in neurobehavioral disorders, Pediatric Neurology 25 (2001), 278–287.
[14] M. Wilke, S. K. Holland, J. S. Myseros, V. J. Schmithorst, W. S. Ball, Functional magnetic resonance imaging in pediatrics, Neuropediatrics 34 (2003), 225–233.
[15] R. R. Price, J. Allison, R. J. Massoth, G. D. Clarke, D. J. Drost, NMR Task Group #8, Practical aspects of functional MRI (NMR Task Group #8), Medical Physics 29 (2002), 1892–1912.
[16] M. Elas, B. B. Williams, A. Parasca et al., Quantitative tumor oxymetric images from 4D electron paramagnetic resonance imaging (EPRI): methodology and comparison with blood oxygen level dependent (BOLD) MRI, Magnetic Resonance in Medicine 49 (2003), 682–691.
[17] P. J. Santosh, Neuroimaging in child and adolescent psychiatric disorders, Archives of Disease in Childhood 82 (2000), 412–419.
[18] R. Turner, T. Jones, Techniques for imaging neuroscience, British Medical Bulletin 65 (2003), 3–20.
[19] R. I. Kuzniecky, R. C. Knowlton, Neuroimaging of epilepsy, Seminars in Neurology 22 (2002), 279–287.
[20] G. Strangman, D. A. Boas, J. P. Sutton, Non-Invasive Neuroimaging Using Near-Infrared Light, Biological Psychiatry 52 (2002), 679–693.
[21] A. Villringer, B. Chance, Non-invasive optical spectroscopy and imaging of human brain function, Trends in Neirosciences 20 (1997), 435-442.
[22] M. E. Moseley, G. H. Glover, Functional MR imaging. Capabilities and limitations, Neuroimaging Clinics of North America 5 (1995), 161-191.
[23] J. E. Desmond, S. H. A. Chen, Ethical issues in the clinical application of fMRI: Factors affecting the validity and interpretation of activations, Brain and Cognition 50 (2002), 482–497.
[24] K. Pacak, E. Eisenhfer, D. S. Goldstein, Functional imaging of endocrine tumors: Role of positron emission tomography, Endocrine Reviews 25 (2004), 568–580.
[25] K. Sudhir, G. Rajshekher, P. Subhashini, Positron emission tomography in neurological diseases, Neurology India 53 (2005), 149–155.
[26] A. Anand, A. Shekhar, Brain imaging technologies in mood and anxiety disorders, Annals of the New York Academy of Science 985 (2003), 370–388.
[27] H. Laufs, J. Daunizeau, D.W. Carmichael, A. Kleinschmidt, Recent advances in recording electrophysiological data simultaneously with magnetic resonance imaging, NeuroImage 40 (2008 ), 515-528.
[28] The ethical brain, M. S. Gazzaniga. Washington, DC: Dana Press, 2005.
[29] Hard science, hard choices: facts, ethics, and policies guiding brain science today, S. J. Ackerman. New York: Dana Press, 2006.
[30] Neuroethics: defining the issues in theory, practice, and policy, J. Illes (Ed.) (2006a). Oxford: Oxford University Press, 2006.
[31] D. Coch, Donna, Neuroimaging research with children: ethical issues and case scenarios, Journal of Moral Education, 36 (2007), 1-18.
[32] R. E. Cranford, The neurologist as ethics consultant and as a member of the institutional ethics committee. The neuroethicist, Neurologic Clinics 7 (1989), 697–713.
[33] P. S. Churchland, D. J. Roy, B. E. Wynne, R. W. Old (Eds.), Our Brains, our selves - reflections on neuroethical questions, Bioscience–society New York: John-Wiley and Sons. (1991), 77–96.
[34] A. A. Pontius, Neuroethics vs neurophysiologically and neuropsychologically uninformed influences in child-rearing, education, emerging hunter-gatherers, and artificial intelligence models of the brain. Psychological Reports 72 (1993), 451–458.
[35] J. Illes, T. A. Raffin, Neuroethics: An emerging new discipline in the study of brain and cognition, Brain and Cognition 50 (2002) 341–344
[36] The risk that failed, W. Safire.NY Times (Print), 2003.
[37] M. Gazzaniga, Facts, fictions and the future of neuroethics. In Neuroethics, Illes, J., ed. Oxford: Oxford UP, 2006.
[38] J. Illes, S. J. Bird, Neuroethics: A modern context for ethics neuroscience, Trends in Neuroscience, 29 (2006), 511-517.
[39] Neuroethics: Mapping the Field. Conference Proceedings, S. J. Marcus, editor. San Francisco Distributed for Dana Press, 2004.

[40] M. Farah, Neurocognitive enhancement: What can we do and what should we do?, Nature Reviews Neuroscience 5 (2004), 421-425.
[41] M. Farah, Neuroethics: The practical and the philosophical, Trends in Cognitive Science 9 (2005), 34-40.
[42] M. Farah, P. Wolpe, Monitoring and manipulating brain function: New neuroscience technologies and their ethical implications, Hastings Center Report 34 (2004), 34-45.
[43] A. I. Leshner, Ethical Issues in Taking Neuroscience Research from Bench to Bedside, Cerebrum 6 (2004), 66-72.
[44] T. Fuchs, Ethical issues in neuroscience, Current Opinion in Psychiatry 19 (2006), 600–607.
[45] http://www.neuroethics.upenn.edu/brain_imaging.html
[46] J. Illes, Empirical neuroethics. Can brain imaging visualize human thought? Why is neuroethics interested in such a possibility?, EMBO Report 8 (2007), 57-60.

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# Social Prospecting

Andrew J. MARSH [a, 1], Christos G. BINIARIS [b], Irene S. KARANASIOU [c] and Denis CARROLL [a]
[a] *University of Westminster, UK*
[b] *VMW Solutions Ltd., UK*
[c] *School of Electrical & Computer Eng., National Technical Univ. of Athens, Greece*

**Abstract.** The goal of social prospecting is to steer the user community into defining the guidelines for self care and lifestyle management. Using an evidence based approach, social prospecting combines the interest in keeping personal or family health care records with the momentum of user-generated healthcare (or health 2.0). The personal healthcare record containing self-documented and self-collected information, or observations, can be used when a symptom or concern arises to identify a retrospective pathology. Coalesce of individual pathologies, related to a particular symptom or concern, can correlate a generic pathology or pathway in the self care domain. Using health 2.0 technologies, the user community can augment these *self care pathways* with advice, suggestions and recommendations and collectively define self care guidelines.

**Keywords.** Social Networking, Health 2.0, self care pathways, PHR.

## 1. Introduction

Personal health management represents a growing market. Sales of home tests are booming. In the UK alone over €80 million was spent on DIY health tests in 2003. The money went on everything from the basic pregnancy tests to male fertility tests. Six in 10 Britons, for example, have at least 1 self-diagnostic product at home, with the simple thermometer being the most popular [1].

These days, many people are much more aware of their health and often want to try to prevent illnesses before they start, rather than taking medicines once the illness has started to happen. They also realise that identifying the symptoms early on can really improve the chances of staying healthy. An early diagnosis may detect a disorder at an easily treatable stage. However, the degree to which self care becomes more important over the next 20 years will depend on the degree to which the public engages with health care [2]. Self-care is one of the best examples of how partnership between the public and the health service can work [3, 4]. The health service can support a pro-active public in promoting self-care by, for example, helping people to empower themselves with appropriate information, skills and equipment or supporting people to take a more active role in the diagnosis and treatment of a condition followed by rehabilitation and maintenance of well being.

In addition, there has been increasing interest in self-care as a potential role-player in health care provision [5, 6, 7]. Existing knowledge about self-care however, is

[1] Corresponding Author: Visiting Professor Andrew Marsh, University of Westminster, 115 new Cavendish street, Westminster, UK ; Email: am@vmws.com

regarded as insufficient and assessment of information emanating from self-care users is extremely difficult due to the lack of control regarding the conditions (e.g. devices used to acquire data, environmental conditions during the measurement, other parameters, such as whether the patient is standing, sitting etc) as well as the inherently subjective nature regarding the qualitative description of a patient's situation (e.g. two persons with the same condition may experience and describe this condition in totally different ways).

What is more, is the boom in "user-generated content" is also addressing healthcare [8, 9, 32]. Millions are now logging on to contribute information about topics stretching from aviation flu pandemics to the extraction of wisdom teeth. The "Economist" terms this *user-generated health care* or *Health 2.0* [10, 11]. Five years ago, online content generated by individual web surfers was seen as something done by the technically gifted. Keeping a 'blog' was akin to being a computer coder. In recent years, there has been an incredible boom in user-generated content and it is estimated that a new blog is created every 5 seconds [12]. Wikipedia is an online encyclopaedia written by thousands of global users. Even more recently, 'social networking' portals have become some of the most popular web sites, offering users a chance to connect to peers worldwide. For example, UK participation in social networking was revealed to be the highest in Europe, with 24.9 million unique visitors – 78% of the total adult online population – now belong to the UK's social networking community.

The objective of *social prospecting* is to harness this momentum in user-generated healthcare (or health 2.0) [29, 30] combined with personal healthcare records and focus the online community into defining guidelines for self care and lifestyle management. Collectively the recorded information can become a powerful tool regarding early prediction of symptoms or concern and identifying retrospective pathologies. In this context, *Self care* can be considered as a set of measures taken in advance of symptoms to prevent illness or injury. This type of care is best exemplified by routine physical examinations and immunizations. The challenge behind this approach is to tame the huge entropy of this information and attempt to extract guidelines generated by the users themselves [26, 27].

The paper is divided into three main sections followed by conclusions. In the next section care pathways are introduced. Care pathways have been derived from clinical guidelines and provide a means for identifying the pathology of a disease or condition. Care pathways have been derived primarily for clinical use. Section 3, reports the growing interest in keeping personal or family healthcare records. By combining these records, care pathways and user-generated guidelines can be created. Section 4 presents Social Prospecting as a way to define care pathways and subsequent guidelines for self care and lifestyle management. Conclusions are presented in section 5.

## 2. Care pathways

Clinical Care Pathways were introduced in the early 1990s in the UK and the USA, and are being increasingly used throughout the developed world [13]. Clinical Care Pathways are structured, multidisciplinary plans of care designed to support the implementation of clinical guidelines and protocols aiming to improve, in particular, the continuity and co-ordination of care across different disciplines and sectors [14, 15]. They are designed to support clinical management, clinical and non-clinical resource management, clinical audit and also financial management. They provide detailed

guidance for each stage in the management of a patient (treatments, interventions etc) with a specific condition over a given time period, and include progress and outcomes details [16, 17].

Practically, Care pathways are plans of how someone should be cared for when they have a particular medical condition or set of symptoms [18]. They can be viewed as algorithms in as much as they offer a flow chart format of the decisions to be made and the care to be provided for a given patient or patient group for a given condition in a step-wise sequence. A Care Pathway maps out a pre-defined set of activities and/or choices within a specified scope, which may be applied to one or more issues or problems. One of the best examples of an online implementation of care pathways, and used in the UK NHS, is the Map of Medicine [19].

### *2.1 The Map of Medicine*

The Map of Medicine® is an online clinical knowledge browser that provides desktop access to specialist clinical knowledge and evidence-based practice across primary and secondary care, working in partnership with the National Library for Health (NLH). The Map of Medicine represents best practice that has been distilled from guidance (e.g. from NICE), clinical protocols and clinical evidence; it is organised into over 300 "patient pathways" spanning: Accident and Emergency, medicine, obstetrics, gynaecology, oncology, palliative care, paediatrics, radiology, surgery and mental health. Each page and node in the pathway may have supporting contextual information and is an access point to NLH and third party guidance, evidence, research, and patient resources, as shown in Figure 1. This supports the practice of evidence-based medicine (EBM).

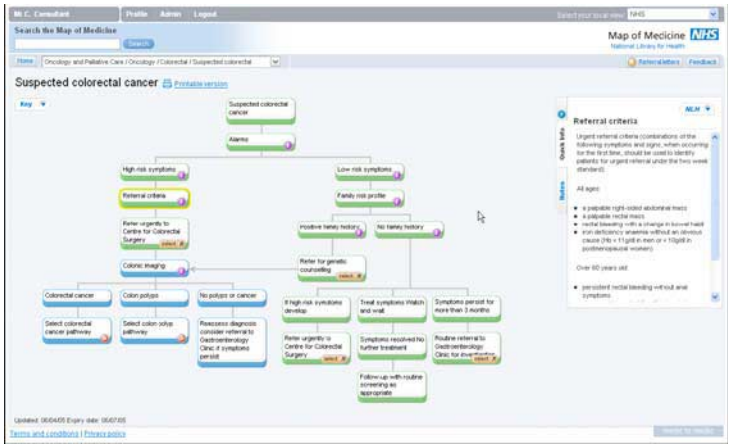


Figure 1: Map of Medicine - Suspected Colorectal Cancer

### *2.2 Preventative Care Pathways*

The starting point of any Care Pathway is the "Symptoms or Concern", which defines the point at which the medical practitioner's participation begins, for example entry to a Chronic Heart Disease (CHD) Care Pathway. In retrospect, in order to reach these symptoms or concern, the patient has followed another pathway which had probably begun due to family history conditions and has followed a specific route influenced by

lifestyle, habits or other related events. This pathway, if known, could have been altered and consequently could have resulted in the entry to the Care Pathway being avoided. However, there must be a procedure to collect information regarding

a) Lifestyle conditions
b) minor symptoms which are not considered as important to request medical advice
c) possible symptoms that the person regards as relevant to other causes

There also needs to be a process which compares this collected information against what is expected. The problem is there are no guidelines on what should be expected and subsequently how to prevent the symptoms or concern. The premise of social prospecting is that a series of steps or waypoints do exists, depicted in Figure 2, between a patient's family history and symptoms or concern. If these waypoints become documented a pathway, termed *preventative pathway*, can be constructed. Preventative pathways can then be used to produce self care guidelines

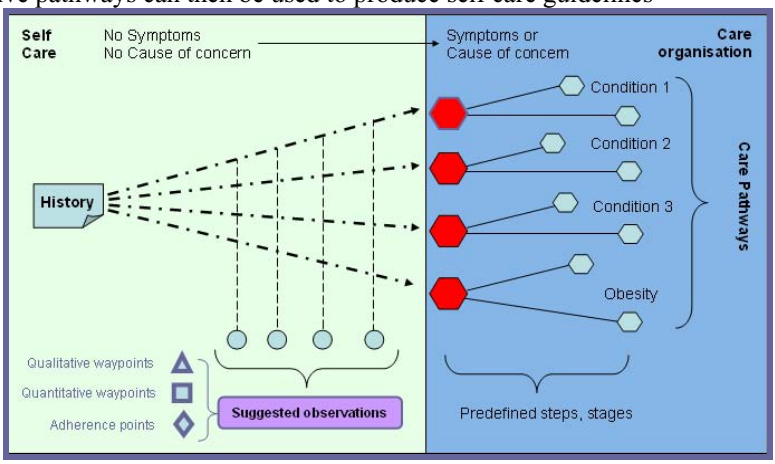


Figure 2. Preventative care pathway

## 3. The quest for healthy living with our PHR

Results from a US nationwide survey by Harris Interactive in 2004 indicated that two in five (42%) adults keep a personal or family record that is "one place where you keep all your medical records with the results of all your medical tests and details about prescriptions, vaccinations, treatments, known allergies and other health care information". Almost every one (84%) of those who do not keep health records thinks it would be a good idea to do so. At the moment, only a small minority (13%) of those with health records keep them electronically but many – 40% of all those who do not have electronic medical records- think it at least somewhat likely that they will do. Women (45%) are slightly more likely than men (38%) to keep personal or family medical records and older people (58% of 65+) are more likely than younger people to keep personal or family medical records. Of those who keep records 95% keep them for themselves, 51% for their spouse and 38% for their children. One of the many "good reasons" for keeping records is the ability to provide doctors with useful information (78%) [20].

## 4. Social Prospecting

The goal of social prospecting is to steer the user community into defining the guidelines for self care and lifestyle management. The personal healthcare record containing self-documented and self-collected information, or observations, can be used when a symptom or concern arises to identify a retrospective pathology. Coalesce of individual pathologies, related to a particular symptom or concern, can correlate a generic pathology or pathway in the self care domain. Using health 2.0 technologies [21, 22, 23], the user community can augment these *self care pathways* with advice, suggestions and recommendations and collectively define self care guidelines.

In the first instance, self care pathways will be analogous to preventative care pathways in the sense that they will identify a pathway from *family history* to a *symptom or concern* relating to a entry point of a Care Pathway, for example the CHD (Chronic Heart Disease) Care Pathway.


Figure 3: A generic Self care pathway

Motivation is key to social processing because only if a large population are willing to contribute can a fair consensus and common pathologies be identified. Social processing therefore makes use of the Personal Healthcare Record (PHR) by using anonymised non-personalised information to derive consensus and correlations. A PHR can include self-collected and self-documented observations containing quantitative and qualitative information. These observations, depicted in Figure 4, are joined by a timeline. Quantitative observations (Qt) typically relate to properties, such as blood pressure, weight, pulse etc whereas qualitative observations (Ql) typically relate to symptoms, headache, chest pain etc.

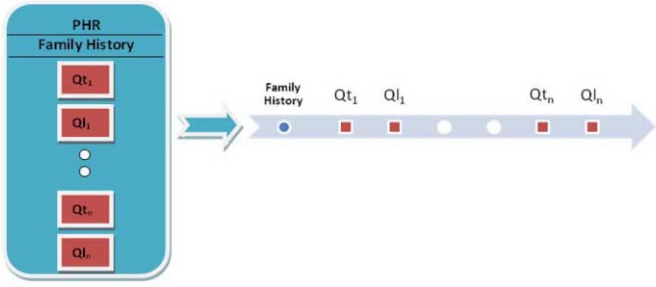


Figure 4: PHR timeline of observations

When a patient has an identifiable symptom or concern, for example they visit their GP with a chest pain and their GP decides they enter the CHD Care Pathway, their respective PHR timeline with non-personalised observations can be coalesced with other similar PHR timelines. With a large enough population and using an AI inference engine [28], the common CHD preventative Care Pathway can be derived, as depicted

in Figure 5 and presented in the social prospecting portal as a hypermedia flowchart. Using web 2.0 technologies each preventative Care Pathway can be augmented with user suggestions, advice and recommendations providing guidelines for self care and lifestyle management.

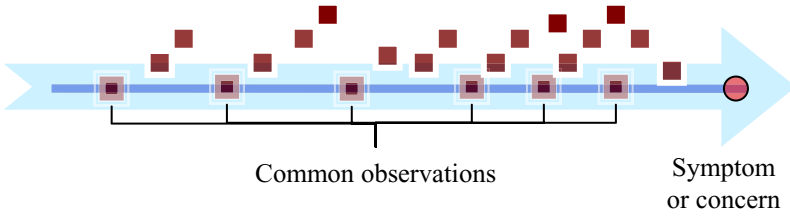


Figure 5: Building the generic self care pathway

In order to correlate quantitative ($Q_t$) observations from different PHR's there needs to be a common terminology. This is achieved by using SNOMED CT terms derived from the consumer healthcare device making the observation. To correlate qualitative ($Q_l$) observations is more difficult because there is no equivalent terminology for defining symptoms. The approach adopted by *social prospecting* is to allow the user-generated community to define these terms through consensus. An initial taxonomy has been suggested, built from the NHS self help guide, but through collective opinion can be refined, but terms can not be removed. For example, for a pain in the chest observation, the user could tag the observation with either *chest pain* or a more detailed description such as *chest pain + feeling faint*.

With self care pathways defined, the patient can submit their PHR to the social prospecting portal for comparison against identified trends and pathologies and automatically receive advice, suggestions and guidelines.

## 5. Conclusions

Whereas social networking portals typically consist of wiki style structures [24, 25] encouraging a continuing dialogue and consensus on given content, social prospecting is promoting users to contribute thoughts, recommendations and statements that necessarily do not have to link to any other content, but joined by a timeline, and store these as part of their PHR as observations.

Coupled with information from consumer healthcare devices, the self-collected and self-documented observations contribute to consensus of opinion when combined with other patient's observations with similar symptoms or concern. Using Evidence Based Medicine techniques, the social prospecting platform, with its AI inference engine, assembles a preventive care pathway for each identified symptom or concern (i.e. entry point to a care pathway).

Analogous to training a neural networking, the social prospecting platform using learning technologies to refine its initial estimation identifies a pathway of common observations. The pathways are presented in a social networking portal, as a hypermedia flowchart. Each pathway encourages the user-generated healthcare community to add, annotate and augment with suggestions, recommendations and advice.

## References


[1] Diagnostic, Monitoring and Assistive Tools, Devices, Technologies and Equipment to Support Self Care, Full review report, Department of Health, UK, August 2005.
[2] Self Care – A Real Choice, http://www.dh.gov.uk/SelfCare
[3] Information for health: an information strategy for the modern NHS. Leeds: NHS Executive, 1998.
[4] K. Dean and I. Kickbusch, Health related behavior in health promotion: utilizing the concept of self care,Health Promotion International, Vol. 10, No. 1, 35-40, 1995
[5] S Shoor, K.R. Lorig, Self-Care and the Doctor-Patient Relationship, Medical Care. 40(4) Supplement:II-40-II-44, April 2002
[6] J. Conn, Health 2.0: The next generation of Web enterprises, Modern Healthcare, December 2007, http://www.modernhealthcare.com/apps/pbcs.dll/article?AID=/20071211/FREE/312110003/
[7] K.K. Bhuyan ,Health promotion through self-care and community participation: Elements of a proposed programme in the developing countries, BMC Public Health 2004, 4:11
[8] D. Giustini,. How web 2.0 is changing medicine. *BMJ* 2006;333:1283-4
[9] N. Maged. K. Boulos, S. Wheeler, The emerging Web 2.0 social software: an enabling suite of sociable technologies in health and health care education, Volume 24 Issue 1 Page 2-23, March 2007
[10] Health 2.0, The Economist, Sep 6th 2007
[11] Number of "Cyberchondriacs" – U.S. Adults Who Go Online for Health Information – Increases to Estimated 117 Million, David Kran, Harris Interactive, HealthCare News, 2005, www.harrisinteractive.com/news/newsletters/healthnews/HI_HealthCareNews2005Vol5_Iss08.pdf
[12] E. Barsky,. Introducing Web 2.0: weblogs and podcasting for health librarians. J Can Health Libr Assoc 2006;27:33-4..
[13] T. Benson, Care Pathways, Version 1.0 8, NHS National Programme for Information Technology, August 2005
[14] D.J. Kitchiner, P.E. Bundred, Clinical pathways: A practical tool for specifying, evaluating and improving the quality of clinical practice, Medical Journal of Australia, 1999; 170: 54-55
[15] R. N. Every, J. Hochman, R. Becker, S. Kopecky, C.P. Cannon, Critical Pathways A Review, Circulation. 2000;101:461-465 "
[16] D. Kitchiner, C. Davidson, P. Bundred., Integrated care pathways: effective tools for continuous evaluation of clinical practice, J Eval Clin Pract. 1996 Feb;2(1):65-9.
[17] H. Campbell, R. Hotchkiss, N. Bradshaw, M. Proteous. Integrated care pathways. BMJ 1998; 316: 133-137.
[18] G.R. Wilensky. Consumer-driven health plans: Early evidence and potential impact on hospitals. Health Aff 2006; 25: 174–85.
[19] http://www.mapofmedicine.com
[20] Health Care News, HarrisInteractive, Volume 4 Issue 13, August 10, 2004.
[21] E. Barsky., & M. Purdon. "Introducing Web 2.0: Social networking and social bookmarking". 2006 JCHLA , 27 (3), 65-67
[22] E. Barsky. "Introducing Web 2.0: RSS trends for health librarians". 2006. JCHLA, 27 (1), 7-8.
[23] E. Barsky., A.Cho, Introducing Web 2.0: social search for health librarians. 2007. JCHLA , 28 (2), 59-61
[24] T. O'Reilly, What Is Web 2.0,
[25] J. Hoeksma, Health 2.0 and the future of the NHS, 19 October 2007
[26] R.E. Herzlinger, editor. Consumer-Driven Health Care. San Francisco: Jossey-Bass; 2004.
[27] T.S. Jost, M.A. Hall, The role of state regulation in consumer driven health care. Am J Law Med 2006; 31: 395–418.
[28] J. Huang, N.R. Jennings, and J. Fox, "An agent based approach to health care management" Int. J. Applied Artificial Intelligence 9 (4) 1995.
[29] T. Oreilly, "What is Web 2.0: Design Patterns and Business Models for the Next Generation of Software". Communications & Strategies, No. 1, p. 17, First Quarter 2007 Available at SSRN: http://ssrn.com/abstract=1008839
[30] D. Giustini, (2007). Web 3.0 and medicine. *BMJ* 335: 1273-1274
[31] K.Dean., Self-care components of lifestyles: the importance of gender, attitudes and the social situation, Soc Sci Med. 1989;29(2):137-52.
[32] http://health20.org/wiki/Main_Page

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# Experimental Study of Fuzzy-Rule Based Management of Tropical Diseases: Case of Malaria Diagnosis

Okure U. Obot[a], Faith-Michael E. Uzoka[b]
[a] *Dept of Mathematics, Statistics and Computer Science, University of Uyo, Nigeria*
*abatakure@yahoo.com*
[b] *Information Systems Group, Department of Accounting and Finance, University of Botswana*
*uzokaf@mopipi.ub.bw*

**Abstract**. The application of the conventional symbolic rules found in knowledge base technology to the management of a disease suffers from its inability to evaluate the degree of severity of a symptom and by extension the degree of the illness. Fuzzy logic technology provides a simple way to arrive at a definite conclusion from vague, ambiguous, imprecise and noisy data (as found in medical data) using linguistic variables that are not necessary precise. In order to achieve this, a study of a knowledge base system for the management of diseases was undertaken. The Root Sum Square of drawing inference was employed to infer the data from the rules developed. This resulted in the establishment of some degrees of influence on the diseases. Using malaria as a case study, a system that uses Visual Basic .Net development environment was developed and the results of the computations are presented in this research.

Keywords. Fuzzy, rule base, diagnosis, malaria, tropical diseases

## 1. Introduction

Medical diagnosis involves the elicitation of symptoms, observation of signs and the interpretation of specific diagnostic investigation. It is dependent on the expertise, experience and skills of a medical practitioner. Medical diagnosis and treatment of tropical diseases involve a state space search of medical knowledge of tropical diseases, patient history, drugs and other cognitive and emotional variables [1]. In order to ensure that this onerous task is undertaken with ease, the National Basic Health Services Scheme which contains standing orders that define how a patient should be cared for in the absence of a qualified medical doctor is provided and discussed in [1]. The standing orders are a high level abstraction of the combined static and dynamic knowledge of a team of seasoned medical doctors and other medical personnel involved in the management of tropical diseases. When such knowledge is presented in

a computer readable form to ensure speed and accuracy of processing, it is called a knowledge based system. Knowledge based systems using symbolic rules for the diagnosis and treatment of some tropical diseases are presented in [1], [2], [3], [4], [5], and [6].

Though symbolic rules enable modular systems to be built and a lot of human reasoning can be expressed, symbolic rules are brittle when presented with noisy data that contains unexpected values and incomplete data with missing values. In addition, data with non-linear relationships as witnessed in medical database are usually difficult to express by symbolic rules. Rules are also time consuming and prone to error when coded manually [7]. Knowledge-based using symbolic rules are unable to spell out the degree to which a patient suffers from a disease; for example, the degree of severity of symptom or mildness of a disease. This is indeed how a human expert (medical doctor) reasons. With rapidly advancing technology, the dream of producing machines that mimic human reasoning, based on uncertain and imprecise information has captured the attention of many researchers. The theory and application of fuzzy logic concepts are central in this regard [8]. [9] postulates that meaning in natural language is a matter of degree. Fuzzy logic provides an inference morphology that enables approximate human reasoning capabilities to be applied to knowledge-centered systems. When a symbolic rule base is fused in a fuzzy rule-base to achieve a knowledge based system, the resultant architecture gives a robust, improved performance and an increased problem-solving capabilities system. The applications of fuzzy concepts to medical diagnosis of some diseases are discussed in [10], [11], [12], [13], and [14].

The objective of this research is to apply the concept of fuzzy logic technology to determine the degree of severity or degree of influence to the symptoms and diseases evaluated in [2] which already applied the knowledge technology to the management of tropical diseases. [2] can be found on www.emeraldinsight.com/0952-6862.htm. This study therefore extends the results already obtained in [2] by:

a) Development of fuzzy expressions and fuzzy rules that are later used to extract the degree of membership to fuzzify the data obtained in [2].
b) Application of the root sum square of drawing fuzzy inference procedure to the fuzzified dataset.
c) Defuzzifying the dataset to crisp output using the fuzzy centroid method.

In Section 2 of the paper, the research methodology is presented, the research experiment is presented in Section 3 while in Section 4, the discussion of the results obtained from the experiment are presented and some conclusions are drawn.

## 2. Research Methodology

The fuzzy logic of the diagnosis of tropical diseases involves fuzzification, inference, defuzzification. The basic flow of information of the fuzzy logic mechanism is illustrated in figure 1.

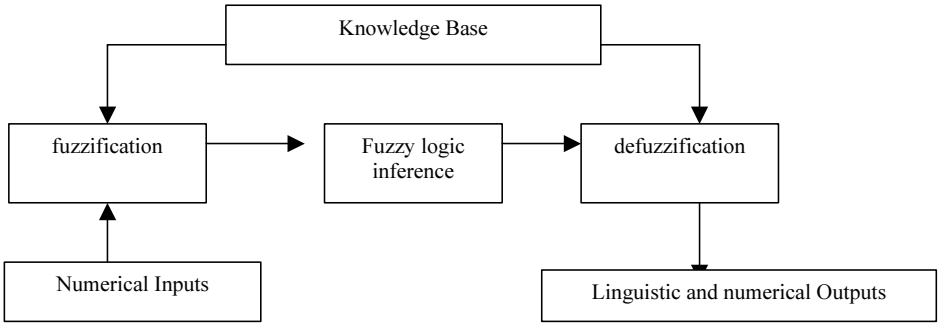


Figure 1: Empirical model of fuzzy logic of Diagnosis of Tropical Disease.

The knowledge base for tropical diseases contains both static and dynamic information. There are qualitative and quantitative variables, which must be fuzzified, inferred and defuzzified. Fuzzification begins with the transformation of the raw data using the functions that are expressed in equations (1) – (5). During the process, linguistic labels are attached to the symptoms and the diagnostic steps which according to [2] are accompanied by associated degrees of intensity rated on a likert scale of 1-5. The function for the linguistic labels is defined in equation 1 as:

$$Symptom(x) = \begin{cases} very\,mild & if \quad x < 0.1 \\ mild & if \quad 0.1 \le x \le 0.3 \\ \mathrm{mod}\,erate & if \quad 0.3 \le x \le 0.6 \\ severe & if \quad 0.6 \le x \le 1.0 \\ very\ severe & if \quad x \ge 1.0 \end{cases} \tag{1}$$

The linguistic labels are later assigned some degrees of membership ($U_x$) as expressed in equations (2) to (5) for mild, moderate, severe and very severe labels:

$$Mild(x) = \begin{cases} 0 & if \quad x \le 0.1 \\ \dfrac{x - 0.1}{0.2} & if \quad 0.1 \le x \le 0.4 \\ 0 & if \quad 0.4 \le x \end{cases} \tag{2}$$

$$Moderate(x) = \begin{cases} 0 & if \quad x < 0.3 \\ \dfrac{x - 0.3}{0.3} & if \quad 0.3 \le x \le 0.5 \\ \dfrac{0.7 - x}{0.3} & if \quad 0.5 \le x < 0.7 \\ 0 & if \quad 0.7 \le x \end{cases} \tag{3}$$

$$Severe(x) = \begin{cases} 0 & if \quad x < 0.6 \\ \dfrac{x - 0.6}{0.6} & if \quad 0.6 \le x \le 0.8 \\ \dfrac{1.0 - x}{0.6} & if \quad 0.8 \le x \le 1.0 \\ 0 & if \quad 1.0 \le x \end{cases} \tag{4}$$

$$Very\ severe(x) = \begin{cases} 0 & if \quad x < 0.9 \\ \dfrac{x - 0.9}{0.9} & if \quad 0.9 \le x < 1.0 \\ 0 & if \quad 1.0 \le x \end{cases} \tag{5}$$

In equation (1), linguistic labels are assigned to the signs and symptoms of a disease, whereas in equations (2) – (5), each of the labels is assigned a value to emphasize the degree of the label assigned in (1). For instance, equation 3 evaluates the degree of modesty of the signs and symptoms, if say the value of a symptom is 0.5, then the degree of severity will evaluate to 0.67 (67%) severity, if it is 0.6, then it becomes 0.33 (33%). The graph is a smooth normal curve as depicted in Figure 2.

The next step in the fuzzification process is the development of fuzzy rules. The fuzzy rules for this research were developed with the assistance of seven medical doctors (domain experts). There are twenty diseases in the knowledge base [2] and each disease has 32 sets of fuzzy rules. The rules for malaria disease have weight loss, fever, headache, loss of appetite and plasidium parasite in blood as premise parameters. These are used to generate thirty two fuzzy rules, some of the rules are as follows:

R1 If weight loss = very mild, and fever = mild and headache = mild and loss Appetite = mild and malaria parasite = positive(mild) Then malaria =mild

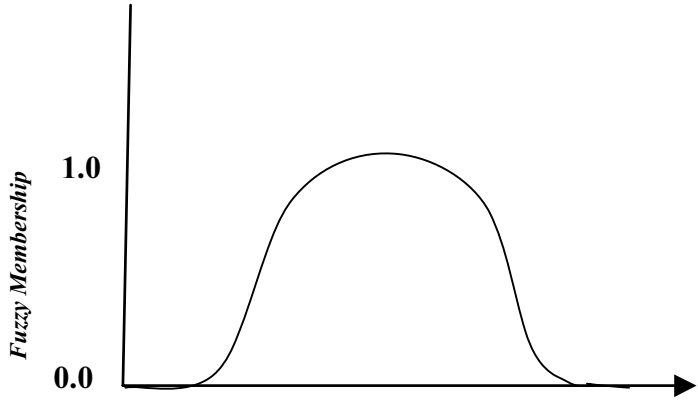


Figure 2: Fuzzy Membership Graph

R5 If weight loss = mild and fever = severe and headache = moderate and loss Appetite = mild and malaria parasite = positive(moderate) Then malaria = moderate

R10 If weight loss = very mild and fever = moderate and headache = severe and loss Appetite = moderate and malaria parasite = positive( severe). Then malaria = severe

R15 If weight loss = moderate and fever = severe and headache = severe and loss Appetite = moderate and malaria parasite = negative. Then malaria = mild.

R20 If weight loss = severe and fever = very severe and headache = moderate and loss Appetite = mild and parasite = positive (moderate) Then moderate = severe

R21 If weight loss = very mild and fever = mild and headache = sever and loss Appetite = moderate and parasite = positive (very sever), Then malaria = very severe.

R23 If weight loss = sever and fever = mild and headache = mild and loss Appetite = moderate and parasite = positive (moderate). Then malaria = moderate.

R25 If weight loss = very severe and fever = mild and headache = mild and loss Appetite = severe and parasite = positive (moderate), then malaria = severe.

R28 If weight loss = mild and fever = mild and headache = mild and loss Appetite = mild and parasite = negative then malaria = mild.

R30 If weight loss = moderate and fever = moderate and headache = mild and loss Appetite = mild and parasite = moderate then malaria = moderate

These fuzzy rules as translated to fuzzy rule base is presented in Table 1:

Table 1: The System Rule Base

| Rule No. | Weight loss | Fever | Headache | Loss of Appetite | Malaria parasite | Conclusion |
|---|---|---|---|---|---|---|
| 1 | Very mild | Mild | Mild | Mild | Positive (mild) | Mild |
| 5 | Mild | Severe | Moderate | Mild | Positive(moderate) | Moderate |
| 10 | Very mild | Moderate | Severe | Mild | Positive(severe) | Moderate |
| 15 | Moderate | Severe | Severe | Moderate | Negative | Severe |
| 20 | Severe | Very severe | Moderate | Mild | Positive(moderate) | Severe |
| 21 | Very mild | Mild | Severe | Moderate | Positive(very severe) | Very severe |
| 23 | Severe | Mild | Mild | Moderate | Positive(moderate) | Moderate |
| 25 | Very severe | Mild | Mild | Severe | Positive(moderate) | Severe |
| 28 | Mild | Mild | Mild | Mild | Negative | Very mild |
| 30 | Moderate | Moderate | Mild | Mild | Positive(moderate) | Moderate |

A rule is said to fire if any of the precedence parameters (very mild, mild, moderate, positive, severe) evaluate to true (1); otherwise, if all the parameters evaluate to false (0) it does not fire.

*2.1. The Fuzzy Inference*

After a particular disease has been determined and all the cognitive and emotional rankings are performed through the algorithm presented in [2], the fuzzy inference process is performed to determine the degree of influence on the fuzzy parameter. For example, a patient may have been suspected to have malaria; this is fuzzy in the sense that the exact degree of malaria is not determined. What the fuzzy logic system does is to determine this exactness and certainty thereby minimizing ambiguities. The fuzzy inference employed in this research is the Root Sum Square (RSS). RSS is given by the formula $\sqrt{\sum r^2}$ . This method combines the effects of all applicable fuzzy rule, scales the function at the respective magnitudes, and computes the 'fuzzy' centroid of the composite area [10]. This method, though complicated gives the best weighted influence to all firing rules. For example, in the rule base in Table 2,

$$\text{Moderate membership function strength} = \sqrt{R_5^{\,2} + R_{10}^{\,2} + R_{23}^{\,2} + R_{30}^{\,2}} \quad (6)$$

$$\text{Severe membership function} = \sqrt{R_{15}{}^2 + R_{20}{}^2 + R_{25}{}^2} \quad (7)$$

For instance the severe function (equation) can be interpreted as: Square the value of rule 15 and add to the square value of rule 20, add the results to the square value of rule 25 and then find the square root of the result.

**Defuzzification**: The defuzzification interface is a mapping from a space of fuzzy actions defined over an output universe of disclosure into a space of non-fuzzy actions. This is due to the fact that the output from the inference engine is usually a fuzzy set, while for most real life applications, crisp values are often required. The three common defuzzification techniques are: *max-criterion*, *center-of-gravity* and the mean of maxima. Though the max criterion is the simplest to implement because it produces the point at which the possibility distribution of the action reaches a maximum value [15], the CoG method is adopted in this study because it is more accurate in representing fuzzy sets of any shape [16]. The center of gravity (CoG) is an averaging technique. The difference is that the (point) masses are replaced by the membership values. This method is called the center of area defuzzification method in the case of 1-dimensional fuzzy sets. In a discrete form, COG (crisp output) is defined by:

$$COG(B^O) = \frac{\sum_{q=1}^{N_q} \mu_{B^O}(y_q) y_q}{\sum_{q=1}^{N_q} \mu_{B^O}(y_q)}$$

where $N_q$ is the number of quantization used to discretize membership function

$\mu_{B^o}(y)$ of the fuzzy output $B^o$.

Figure 3 shows the final output of the aggregation using the max-min while Figure 4 shows the center of gravity defuzzification method .

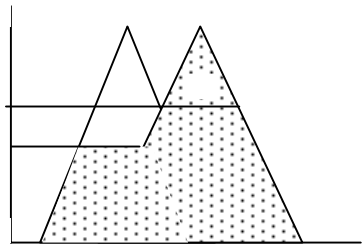

Figure 3: Aggregation output using the max-min method

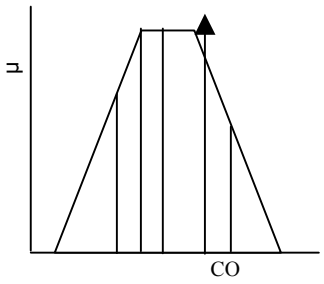


Figure 4: COG defuzzification method

## 3. Research Experiment

The research experiment was conducted using Microsoft Access as the database management system and Visual Basic.Net for the development of the user interface and fuzzy inference. Tables 2 and 3 give the results of the evaluation of the fuzzy rule base inference for patient number 001 and 015 respectively.
The interactive session entered for patient number 001 is as follows:

| | | |
|---|---|---|
| Weight Loss: | | Very mild (0.1) |
| Fever | | Severe (0.8) |
| Headache | Mild | (0.25) |
| Loss of Appetite | Mild | (0.1) |
| Blood Test | Severe | (0.75) |

These values will result in the transcript presented in Table 2 using the rule based as shown in Table 1

Table 2: Rule Base evaluated for patient no 001

| Rule No | Premise variables | | | | | Conclusion Part of rule | Non zero Minimum Value |
|---|---|---|---|---|---|---|---|
| | Weight loss | Fever | Headache | Loss of Appetite | Blood test | | |
| 1 | 0.1 | 0 | 0.25 | 0 | 0.1 | Mild | 0.1 |
| 5 | 0.1 | - | - | - | 0.1 | Moderate | 0.1 |
| 20 | - | - | - | 0.1 | - | Very Severe | 0.1 |
| 21 | 0.1 | 0.8 | - | - | - | Severe | 0.1 |
| 23 | - | 0.8 | 0.25 | - | 0.75 | Moderate | 0.25 |
| 25 | - | 0.8 | 0.25 | - | 0.75 | Severe | 0.25 |
| 28 | 0.1 | 0.1 | 0.25 | 0.1 | - | Mild | 0.1 |
| 30 | - | - | 0.25 | 0.1 | 0.75 | Moderate | 0.1 |

Only 8 rules fire for patient number 001 Deducing the conclusion part of the rule base such that each of the conclusion parameters (membership function) becomes the subject of the formula and the associated non zero minimum values form the arguments, we have:

$$\begin{aligned} Mild &= \sqrt{0.1^2 + 0.1^2} &&= 0.14 \\ Moderate &= \sqrt{0.25^2 + 0.1^2 + 0.1^2} &&= 0.298 \\ Severe &= 0.1^2 + 0.25^2 &&= 0.394 \\ Very\,severe &= 0.1^2 &&= 0.1 \end{aligned} \quad (8)$$

$$Crisp\ output = \frac{(0.15x0.14)+(0.40x0.29)+(0.70x0.39)+(0.90x0.1)}{0.15+0.40+0.70+0.90} = 0.50 \quad (9)$$

This means patient number 001 has moderate malaria with 50% intensity.

The interactive session entered for patient number 015 is as follows:

| | | |
|---|---|---|
| Weight Loss: | | Very mild (0.12) |
| Fever | | Mild (0.4) |
| Headache | Mild | (0.35) |
| Loss of Appetite | None | (0.0) |
| Blood Test | Mild | (0.1) |

These values result in the transcript presented in Table 3 using the rule based as shown in Table 1

Table 3: Rule Base evaluated for patient no 015

| | Premise variables | | | | | | |
|---|---|---|---|---|---|---|---|
| Rule No | Weight loss | Fever | Headache | Loss of Appetite | Blood test | Conclusion Part of rule | Non zero Minimum |
| 1 | 0.12 | 0.4 | 0.35 | - | 0.1 | Mild | 0.1 |
| 10 | 0.12 | - | - | - | - | Severe | 0.12 |
| 21 | 0.12 | 0.4 | - | - | - | Very severe | 0.12 |
| 23 | - | 0.4 | 0.35 | - | - | Moderate | 0.35 |
| 25 | - | 0.4 | 0.35 | - | - | Severe | 0.35 |
| 28 | - | 0.4 | 0.35 | - | - | Mild | 0.35 |
| 30 | - | - | 0.35 | - | - | Moderate | 0.35 |

Only 7 rules fire for patient number 015, the conclusion part of the rule base is deduced as follows:

$$\begin{aligned} Mild &= \sqrt{0.1^2+0.35^2} = 0.36 \\ Moderate &= \sqrt{0.35^2+0.35^2} = 0.50 \\ Severe &= \sqrt{0.35^2+0.12^2} = 0.37 \\ Very\ severe &= \sqrt{0.12^2} = 0.12 \end{aligned} \quad (10)$$

$$Crisp\ output = \frac{(0.15x0.36)+(0.40x0.50)+(0.70x0.37)+(0.9x0.12)}{0.15+0.40+0.70+0.90} = 0.29 \quad (11)$$

The data collected from 15 patients is presented in Table 4 as shown:

Table 4: Data Collection from Malaria Patients

| Patient No | Weight Loss | Fever | Headache | Loss of Appetite | Blood Test |
|---|---|---|---|---|---|
| 001 | Very mild(0.1) | Severe(0.8) | Mild(0.25) | Mild(0.15) | Severe(0.75) |
| 002 | Severe(0.65) | Mild(0.3) | Moderate(0.4) | Severe(0.7) | Mild(0.2) |
| 003 | Mild(0.25) | Moderate(0.5) | Moderate(0.6) | Moderate(0.55) | Mild(0.25) |
| 004 | Severe(0.8) | Moderate(0.5) | V Severe(1.0) | Moderate(0.5) | Severe(0.8) |
| 005 | Severe(0.9) | Severe(0.8) | Severe(0.75) | V Mild(0.1) | Severe(0.8) |
| 006 | Mild(0.2) | Severe(0.65) | Moderate(0.45) | Mild(0.3) | Moderate(0.5) |
| 007 | Severe(0.9) | Moderate(0.6) | Moderate(0.45) | Moderate(0.55) | Moderate(0.6) |
| 008 | Moderate(0.45) | Severe(0.85) | Severe(0.9) | Mild(0.25) | Moderate(0.60) |
| 009 | Severe(0.9) | V Mild(0.1) | Moderate(0.55) | Severe(0.85) | Moderate(0.55) |
| 010 | Severe(0.75) | Severe(0.65) | Severe(0.80) | Moderate(0.45) | Severe(0.60) |
| 011 | Moderate(0.55) | Severe(0.65) | Moderate(0.50) | Moderate(0.45) | Moderate(0.70) |
| 012 | Mild(0.3) | Severe(0.7) | Severe(0.7) | Mild(0.3) | Mild(0.3) |
| 013 | Severe(0.75) | Severe(0.9) | Moderate(0.6) | Moderate(0.5) | Severe(0.7) |
| 014 | Moderate(0.6) | Moderate(0.5) | Moderate(0.45) | Mild(0.2) | Moderate(0.45) |
| 0.15 | V Mild(0.12) | Moderate(4) | Moderate(0.35) | None | Mild(0.15) |

Computations are done as in patient numbers 001 and 015 and the results are presented as shown in Table 5.

Table 5: Results of Fuzzy Logic Computations

| Patient No | Computed RSS Values | | | | | Degree of Diagnosis (crisp output) | Membership Function of Malaria |
|---|---|---|---|---|---|---|---|
| | V Mild | Mild | Moderate | Severe | V Severe | | |
| 001 | - | 0.14 | 0.30 | 0.39 | 0.1 | 0.50 | Moderate |
| 002 | 0.30 | 0.20 | 0.50 | 0.50 | 0.30 | 0.39 | Moderate |
| 003 | 0.25 | 0.20 | 0.53 | 0.45 | 0.25 | 0.35 | Moderate |
| 004 | - | - | 0.87 | 0.94 | 0.50 | 0.73 | Severe |
| 005 | - | - | 1.40 | 1.20 | 0.75 | 1.04 | V Severe |
| 006 | 0.20 | 0.30 | 0.61 | - | - | 0.52 | Moderate |
| 007 | - | - | 1.30 | 1.00 | 0.55 | 0.86 | Severe |
| 008 | 0.25 | 0.25 | 0.43 | 0.51 | - | 0.45 | Moderate |
| 009 | - | 0.25 | 0.55 | 1.00 | - | 0.77 | Severe |
| 010 | - | - | 0.97 | 0.85 | 0.40 | 0.67 | Severe |
| 011 | - | - | 1.00 | 0.67 | 0.45 | 0.64 | Severe |
| 012 | - | 0.3 | 0.52 | 0.76 | - | 0.61 | Severe |
| 013 | - | - | 1.01 | 0.78 | 0.50 | 0.70 | Severe |
| 014 | 0.20 | 0.20 | 0.57 | 0.49 | - | 0.47 | Moderate |
| 015 | - | 0.36 | 0.50 | 0.37 | 0.12 | 0.29 | Mild |

## 4. Discussion of the Results and Conclusion

The results obtained in [2] show that a patient is either diagnosed of a disease ( e.g malaria) or not, that is either "True" or "False". Fuzzy logic represents partial "truth or partial false" in its manipulation. Aside from attaching linguistic variables (mild, moderate etc) to the diagnosis, the degree of mildness, intensity or severity are also evaluated as shown in the cases cited. The symptoms and signs of the disease were also modeled to remove vagueness and ambiguity as presented in Table 2 and Table 3. In addition to this, the final diagnoses show the linguistic labels and the degree of diagnosis. For example, patient number 001 was diagnosed for moderate malaria with 50% modesty while patient number 015 was diagnosed for mild malaria with 29% mildness. The results of these diagnoses and that of 13 other patients are reported and presented in Table 5. This will enable the medical practitioner to assign different doses of treatment to each of the patients according to their degrees of diagnoses. In effect, the issue of abuse of treatment with the attendant financial and social implications will be eliminated.

After a thorough study of the MEPH system proposed in [2], an improvement of the methodology was proposed. The improvement involves the concept of fuzzy logic technology. The symptoms and signs of the diseases were fuzzified. With the help of fuzzy rules developed with the assistance of some medical personnel, the fuzzified variables were composed, inferred and later defuzzified to give the final diagnosis. Fuzzy logic has been shown to relate to probability theory, but with fuzzy logic being able to represent common sense knowledge and addressing the issue of uncertainty and ambiguity of data [17] by determining the exact degree of mildness, modesty and severity of malaria.

A case study of the improved system was developed in Microsoft Access and the Visual Basic.Net environment. The knowledge presented in Table I and II [2] was employed in developing the new system. The system has not been implemented at a commercial level yet, but the results obtained so far are promising. To further optimize the outputs of the research so as to gain the confidence of both the medical practitioners and the patients, a hybrid comprising, neural networks and fuzzy logic, or fuzzy logic and case-based reasoning paradigm is recommended for further study.

## References

[1] O.U. Obot. "Knowledge-based Server for Diagnosis and Therapy of Tropical Diseases", *M. Tech Thesis*, Federal University of Technology, Akure. (1999).

[2] F.M.E Uzoka and F.O. Famuyiwa. "A Framework for the Application of knowledge Technology to the Management of Diseases", *International Journal of Health Care Quality Assurance* 17(4) (2004), 194-204

[3] O.U. Obot. "Experimental study of knowledge Representation in a knowledge-based System (A case study of Diagnosis and Therapy of Typhoid Fever)", *International Journal of Physical Sciences India* , 18 (IM) (2006), 109 –118.

[4] O.C. Akinyokun and O.A Adeniji. "Experimental Study of Intelligent Computer Aided Diagnostic and Therapy", *AMSE Journal of Modeling, Simulation and Control*, 27(3) (1991), 1- 20.

[5] O.U Obot. "Principles, Practice and Problems of Knowledge Acquisition in a Knowledge -based system", *Nigeria Journal of Research and Production,* 5(2)(2004), 36– 42.

[6] F.M.E Uzoka and K. Baker. "AHP-Based Malaria Diagnosis Decision Support System.", *International Conference for eHealth, Telemedicine and Health ICT*, Luxembourg, April 6-8, (2005).
[7] K. McGarry, S. Wermter and J. Maclntyre J. "Hybrid Neural System; from Simple Couple to Fully Integrated Neural Networks", *Neural computing surveys*, 2 (1999), 62-93.
[8] H. T. Nguyen and E.A. Walker. *A First course in Fuzzy Logic, Applications in Intelligent System,* Boston, Kluwer Academic, 1997.
[9] L.I. Kunchewa and F. Steimann F, "Fuzzy Diagnosis", *Artificial Intelligence in Medicin*e, 16(1999), 121-128.
[10] I. Saritas, N. Allahverdi and U. Sert. "A fuzzy Expert System. Design for Diagnosis of Prostrate Cancer", *Proceedings of International Conference on Computer Systems and Technologies*, Kanya, Turkey, 2003.
[11] R. Brause and F. Friedrich. "A Neuro-fuzzy Approach as Medical Diagnostic Interface", *Proceedings of European Symposium on Artificial Neural Networks* (FSANN), 1(2000), 201-206.
[12] C. S. Nunes, M. Mahfouf, D.A. Kinkens and J.E. Peacock. "Modeling and Multivariable Control in Anesthesia using Neural-Fuzzy Paradigms", Artificial *Intelligence in Medicine*, 35(2005), 195 – 206.
[13] O. C. Akinyokun, O.U. Obot, J..J Andy and V.A Aletor. "Design of a Neuro-fuzzy Expert System for the Diagnosis and Therapy of Cardiovascular Diseases", *42nd Annual Conference of science Association of Nigeria Ijebu-Ode, Nigeria*, (2006), 7.
[14] J.C Bezdek. "The Coming Age of Fuzzy Logic", *Proceedings of the IFSA Congress*, Seattle Washington, 1989.
[15] A. Abraham and B. Nath. "Hybrid Intelligent Systems Design – A Review of a Decade of Research", (2000), downloaded on June 22, 2004 from http://citeseer.ist.psu.edu/523093.html
[16] J.K. Cochran and H. Chen. "Fuzzy Multi-criteria selection of object oriented simulation Software for Production System Analysis", *Computers and Operations Research*, 32(2005), 153-168.
[17] O.U. Obot. Neuro-Fuzzy Expert System Model for the Diagnosis and Therapy of Cardiovascular Diseases; A Case Study of Heart Failure, Ph.D Thesis, Federal University of Technology, Akure, Nigeria, 2007

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# Social Network of PESCA (Open Source Platform for eHealth)

Carlos L. SANCHEZ[b], Miguel ROMERO-CUEVAS[a1], Diego M. LOPEZ[c], Julio LORCA[a], Francisco J. ALCAZAR[b], Sergio RUIZ[d], Carmen MERCADO[a] and Pedro GARCIA-FORTEA[a]

[a] *Fundación para la eSalud-FESALUD, Spain*
[b] *Consejería de Innovación, Ciencia y Empresa, Andalusian Government, Spain*
[c] *Departamento de Telemática, Universidad del Cauca, Colombia*
[d] *Revistaesalud.com, Spain*

**Abstract.** Information and Communication Technologies (ICTs) are revolutionizing how healthcare systems deliver top-quality care to citizens. In this way, Open Source Software (OSS) has demonstrated to be an important strategy to spread ICTs use. Several human and technological barriers in adopting OSS for healthcare have been identified. Human barriers include user acceptance, limited support, technical skillfulness, awareness, resistance to change, etc., while Technological barriers embrace need for open standards, heterogeneous OSS developed without normalization and metrics, lack of initiatives to evaluate existing health OSS and need for quality control and functional validation. The goals of PESCA project are to create a platform of interoperable modules to evaluate, classify and validate good practices in health OSS. Furthermore, a normalization platform will provide interoperable solutions in the fields of health-care services, health surveillance, health literature, and health education, knowledge and research. Within the platform, the first goal to achieve is the setup of the collaborative work infrastructure. The platform is being organized as a Social Network which works to evaluate five scopes of every existing open source tools for eHealth: Open Source Software, Quality, Pedagogical, Security and privacy and Internationalization/I18N. In the meantime, the knowledge collected from the networking will configure a Good Practice Repository on eHealth promoting the effective use of ICT on behalf of the citizen's health.

**Keywords:** Social Network, Open Source Software, eHealth, Web platform, Interoperability, Software Evaluation, Normalization

## Introduction

The use of Information and Communications Technologies (ICTs) for information gathering and retrieval is already important in the healthcare sector. The need for new ways to provide more efficient health care services has increased use of the ICTs applications over the past decade 0.

ICTs are revolutionizing the way medicine is learnt by students and healthcare professionals. Scenarios which were just inconceivable just 10 years ago are now real

[1] Corresponding Author: Miguel Romero-Cuevas. Fundación para la eSalud, C/ Marie Curie, 35, Parque Tecnológico de Andalucía, 29590 Campanillas Málaga, Spain. e-mail: mromero@fesalud.org. URL: www.revistaesalud.com

applications of eHealth: patients being treated from a distance, often by a physician in another country or continent, through the use of telehealth; health professionals upgrading their skills through eLearning without needing to leave their countries; or national networks of electronic health records making available a patient's entire medical history at any point of health care and supporting appropriate treatment 0.

Open Source Software (OSS) is an ideal solution for governments, hospitals and other organizations looking for ways to reduce their ICTs budgets without cutting services, as well as for start-ups or small biomedical companies that have a tight budget and cannot afford high ICTs costs. The use of open source architecture eliminates the need of costly software licenses and maintenance agreements, as well as qualified and expensive ICTs staff, and at the same time provides the same, if not greater productivity, efficiency, reliability, product support and security 0.

Despite these advantages, there are some challenges -especially in Spanish speaker countries- in adopting OSS for health: a) Needs for health open standards and OSS, b) Heterogeneous OSS developed without normalization and metrics, c) English predominance as top OSS language, d) Lack of initiatives to evaluate existing health OSS and e) Needs for quality control and functional validation.

The Open Source Platform for eHealth (PESCA)[4] has been designed as a set of interoperable OSS modules, born as a platform to join efforts, open knowledge, tools and governmental resources, enterprises, health institutions and individuals aiming at providing health IT resources to needed communities. The general goal will be complemented by the following specific objectives:

1. Setup the collaborative work infrastructure.
2. Analyze and validate existing open source tools for eHealth and to select the most relevant ones.
3. Support internationalization. Translation of validated software to three languages: Spanish, Portuguese and English.
4. Provide Workflow Management: elaborate agreements and regulations, develop of the Master Project Plan, risk management, to coordinate technical works, budget control for an effective financial management, to facilitate communications among partners, quality control.
5. Evaluate platform scalability for its local and regional implementation.

One of the first goals of the project is to collect a repository of OSS solutions. All the solutions included will first be evaluated and validated under working conditions, also following generally accepted criteria for accomplishing with technical requirements (relevance, feasibility, interoperability, etc).

The repository will be provided by multidisciplinary groups working worldwide to develop useful eHealth tools in Spanish that may be implemented and easily maintained through the Internet community. For this reason, a key step is to setup the collaborative infrastructure, not only offering technological resources but also human resources.

The human community is being organized as a Social Network using an OSS web tool, in which will be combined existing open knowledge and technologies to widespread the practical use of informatics and communications on health management and logistics, diagnosis and treatment methods, follow up of chronic pathologies, and professional interactions for sharing scientific advances or training the staff.

## Structure and Methodology

PESCA platform is organized as a social architecture defined by Scenes, which constitutes its functional units (see Figure 1):

1. Social Network Scene. Social structure made of nodes that are tied by one or more specific types of relations.
2. Content Management Scene. Content imported into or generated from working groups in the course of their operations.
3. GroupWare Scene. Integration of users and working groups into the project.
4. E-Learning Scene. Development of modules for continuing health professional education.
5. Documental Scene. Facilities to edit and to share knowledge.
6. File Scene. Files Management (storage, access, integrity, etc.).

After the necessary scenes are tested, the community will evaluate five Scopes of every existing open source tools for eHealth:

1. Open Source Software. The objective of this scope is to guarantee distributed peer review and transparency of development process.
2. Quality. Testing play an essential part in ensuring the proper development and maintenance of quality standard-based software, ensuring conformance to standards and interoperability specifications.
3. Pedagogical scope. Software will provide a learning and content management environment.
4. Security and privacy. Each software solution must maintain the integrity and confidentiality of electronic protected health data.
5. Normalization. It is not aimed to elaborate new standards and specifications, but to define a set of those which are relevant for each module in the platform, following some interoperability requirements [5].
6. Internationalization/I18N. Internationalization of the platform is one of the main activities when looking a wide use in different Spanish speaker countries in Latin America and the Caribbean.

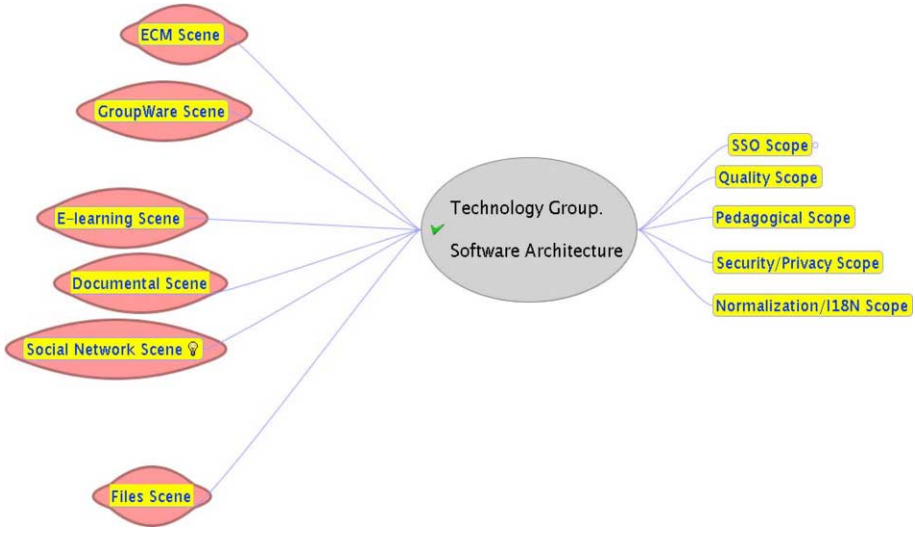


Figure 1. Structure and Methodology in PESCA

The process has to be a continuum, in which PESCA members and users are invited to propose new tools, new methods or standards, and to complete or improve the developments when needed. These kinds of community interactions within the network will configure a Good Practice Repository on eHealth and it is already supporting the creation of a specialized platform for definite open source solutions applied to raise the effective ICT use on behalf of the citizen's health.

## PESCA Social Network

Achieving the goals as outlined in previous section, required a workgroup structure and detailed methodology because of the nature of the project. Overlapping membership of working groups ensures adequate cross-propagation of knowledge. Working groups comprise volunteer members who will meet by communication tools, thus forming a Social Network.

Social networking tools make possible to collect data about members and then store this information as user profiles. The data, or profiles, can then be shared among the members of the site. Social network platforms offer a free and easy way to create personal Web pages and fill them with content such as blogs, digital photographs, short video clips, and much more. Work groups will be formed as members link their Web pages to those of other users and search through the vast number of sites in search of new members who might share common interests [6].

### *Social NetworkingTool*

The first point was to choose between to create an own network or join a public one. The data security requirements and the ability to customize and brand the network according to the specific project needs were the deciding factors to create a specialized, targeted network.

The environment selected is called Elgg, which is an open source social networking platform developed for LAMP (Linux, Apache, MySQL, PHP). The main reasons for choosing Elgg over similar platforms for the purpose of this project were its user-centered approach, as opposed to the more traditional presentation-based view that is employed by most other tools, and the fact that it provides reasonable support for privacy control at a fairly granular level that other tools simply do not have. Furthermore, Elgg provides features: Podcast support, Full access controls, tagging support, User profiles, Full RSS support, RSS aggregator, Creation of Communities, Collaborative community blogs, Creation of 'members' networks, Import content, Publish to blog, Multilingual, Branding/customization, OpenID support, etc.

In November 2007, a version of Elgg was set up on http://redes.epesca.org for testing usability and other issues. During this period the chat tool was installed to provide interactivity to the platform. The final version was released in January 2008, it was the start point for PESCA Social Network.

The main page (see figure 2) is the public area of the site, including blog spots, the tag cloud, the browse link, user's communities and two search boxes. Each member has some tools in his space: Blog, Chat, File manager, Resources, his member's network and a profile editing tool.

*Social Network Milestones*

At the end of February 2008 more than 50 site members from more than 5 countries were registered (60% from ITCs sector and 40% from health and social care sector), more than 67 blog posts, documents, podcasts or video clips on health and ITCs were published, and more than 40 tags describing the subjects: information systems, PESCA, knowledge, eHealth, e-Health, innovation, electronic health record, semantic web, SOAP, open access, investigation, biomedical projects, DICOM, etc. have been created.

The first virtual meeting through the chat was celebrated on January the 17th and 10 members attended. In this meeting the 2008 PESCA roadmap was approved.

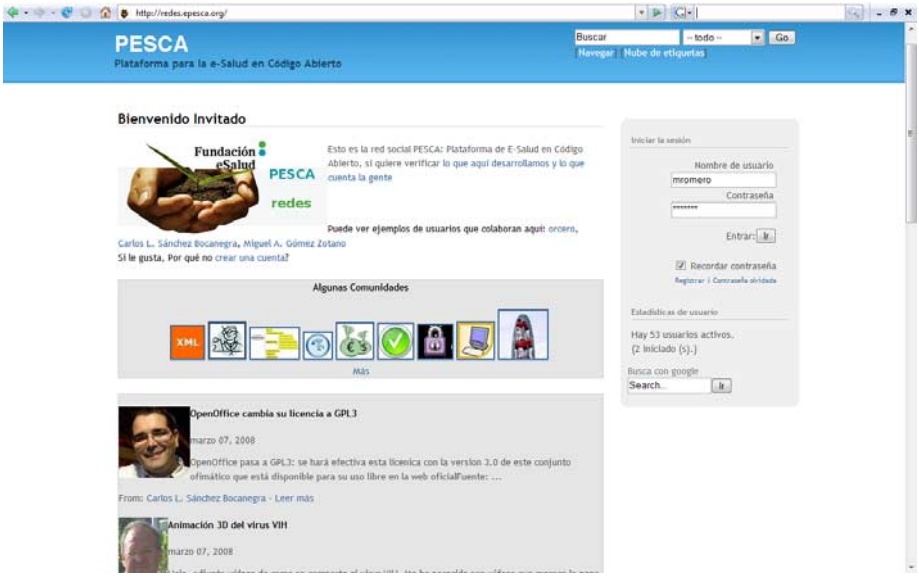


Figure 2. Main page of PESCA community networking platform.

Nine communities (workgroups) have been created. Work is distributed amongst groups identified below, having each one its own mission and leadership: Electronic Health Record, Standards and Normalization, Tools and Applications, Workstations in Primary Care Centres, Privacity in eHealth, Funding and Resources, Health and Social Care Applicatons, Evaluation and Quality, and e-patients.

Some PESCA (sub)projects have been already launched in Argentina and Colombia, and shortly in Venezuela. Social Network is supporting all new initiatives through the redes.epesca.org Web Site.

There are more than 45 OSS health solutions collected on the platform and, in a short period of time, the evaluation and validation of the first one will start.

## Discussion and Conclusions

PESCA is an open source platform to fulfill the existing gaps in the adoption of Health Information technologies, especially in Spanish speaking countries. PESCA is not all about technology, it intends to build a Social Network to support collaboration among

principal actors in eHealth. Also, complementary projects will be created supporting the different health care scenarios all them integrated to the PESCA Platform.

As a result of this first phase of PESCA, an international social network of evaluation and validation of eHealth OSS has been established. The open source social networking platform has demonstrated to be a powerful tool for managing projects, facilitating personal contacts, interactivity, and resources sharing.

These first experiences will lead the development of new eHealth applications. In the near future, people and professionals will be able to adapt PESCA tools to their real necessities: small/local problems or regional issues. The Social network is growing and all partners and collaborators are welcome.

## References

[1] WHO. Information technology In support of health care. Department Essential Health Technologies. http://www.who.int/eht (last accessed February 29th, 2008)

[2] Building Foundations for eHealh. WHO 2007. http://www.who.int/ehealth/resources/bf_full.pdf (last accessed February 29th, 2008).

[3] Camara G, Fonseca F. Information Policies and Open Source Software in Developing Countries. *J. Am. Soc. Inf. Sci. Tech* **58** (2007), 121–132.

[4] Rosa-Valenzuela J, García-Fortea P, Lorca-Gómez J. Proyecto de Plataforma para la e-Salud en Código Abierto (PESCA). RevistaeSalud.com**8** (2006) [ONLINE].

[5] López DM, Blobel B. Connecting Public Health and Clinical Information Systems by Using a Standardized Methodology. In: Proceedings of the 12TH World Congress on Health (Medical) Informatics. *Studies in Health Technology and Informatics*. **129** (2007), 132 -36. (Best Student Paper Award)

[6] Barsky E, Purdon M. Introducing Web 2.0: social networking and social bookmaking for health librarians. *JCHLA / JABSC* **27** (2006), 65–67.

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*IOS Press, 2008*


# The Need for the Use of XACML Access Control Policy in a Distributed EHR and Some Performance Considerations

Snezana SUCUROVIC[a] and Veljko MILUTINOVIC[b]
[a]*Institute Mihailo Pupin, Belgrade, Serbia*
[b]*Faculty of Electrical Engineering, Belgrade, Serbia*

**Abstract.** The Internet based distributed large scale information systems implements attribute based access control (ABAC) rather than Role Based Access Control (RBAC). The reason is that the Internet is identity less and that ABAC scales better. EXtensible Access Control Markup Language is standardized language for writing access control policies, access control requests and access control responses in ABAC. XACML can provide decentralized administration and credentials distribution. In year 2002 version of CEN ENV 13 606 attributes have been attached to EHCR components and in such a system ABAC and XACML have been easy to implement. This paper presents writing XACML policies in the case when attributes are in hierarchical structure. It is presented two possible solutions to write XACML policy in that case and that the solution when set functions are used is more compact and provides 10% better performances.

**Keywords.** Computer security, access control, eXtensible Access Control Markup Language

## Introduction

Access control is the process of mediating every request to data and services maintained by a system and determining whether the request should be granted or denied. A typical access control and authorization scenario includes three main entities -- a subject, a resource, and an action -- and their attributes. A subject makes a request for permission to perform an action on a resource. For example, in the access request, "Allow the finance manager to create files in the invoice folder on the finance server", the subject is the "finance manager," the target resource is the "invoice folder on the finance server," and the action is "create files." In such a context "It is allowed to the finance manager to create files in the invoice folder on the finance server" is the part of a security policy.

In a healthcare information system, for example, access control to a medical record can be limited only to users with an appropriate role and belonging to a provider and the access can be allowed only during an episode of care. According to Comitee European de Normalisation [1] ENV 13606 access control model “Role”, “Healthcare agent” and “Episode of care” are to be attributes of medical record. It is supposed that security policy is “If a user presents the same attributes as they are connected to a medical record, access will be allowed.” That is, a user has to present his attributes: role, provider and episode of care. The problem which is considered in this paper is related

to CEN 13606 based access control in large scale healthcare information systems such as national and regional electronic healthcare record. The main problem in such an information system is that there are large numbers of attributes. Control of them can be simplified if they are hierarchically organised [2], [3].
XACML is an OASIS [4] standard that describes both a policy language and an access control decision request/response language (both written in XML). The typical setup is that someone wants to take some action on a resource, so the elements of request are user's tributes, action and resource to be accessed. The request/response language lets you form a query to ask whether or not a given action should be allowed and interpret the result. The response always includes an answer about whether the request should be allowed using one of four values: Permit, Deny, Indeterminate or Not Applicable.
The currency that XACML deals in is attributes. Attributes are named values of known types. Specifically, attributes are characteristics of the subject, Resource, Action or Environment in which the access request is made. A user's name, their security clearance, the file they want to access, and the time of day are all attribute values. When a request is sent to a Policy Decision Point (PDP) (which makes decision), that request is formed almost exclusively of attributes, and they will be compared to attribute values in a policy to make the access decision.

## 1. CEN ENV 13 606 Access Control Model

The main item in the CEN healthcare information system architecture (CEN, 2002) standard is an Architectural Component. The Architectural Components are organised in a hierarchical structure. Each Architectural Component has a reference to access control list for that component defined as Distribution Rules. A Distribution Rule comprises classes Who, Where, When, Why and How which define who, where, when, why and how is allowed to access the component (Table 1). To access the system a user presents his attributes that correspond to attributes of class Who, When, Where, Why and How. Classes Who, When, Where, Why and How are processed with operator AND. There can be one or more DR attached to AC and they are processed with operator OR.

**Table 1**. Distribution Rule's Attributes

| Class | Attribute | Type |
|---|---|---|
| Who | Profession | String |
| | Specialisation | String |
| | Engaged in care | Boolean |
| | Healthcare agent | Class |
| When | Episode of care | String |
| | Episode reference | String |
| Where | Country | String |
| | Legal requirement | Boolean |
| Why | Healthcare process code | String |
| | Healthcare process text | String |
| | Sensitivity class | String |
| | Purpose of use | Class |
| | Healthcare party role | Class |
| How | Access method | String |
| | Consent required | Class |
| | Signed | Boolean |
| | Encrypted | Boolean |
| | Operating system security rating | String |

| | | |
|---|---|---|
| | Hardware security rating<br>Software security rating | String<br>String |

## 2. The Need for the Use of XACML Access Control Policy

XACML is being increasingly adopted in large enterprise systems for specifying access control policies. It provides decentralized policies and their integration in such large distributed systems with multiple autonomous parties. Without standardized access control language, managing access control in such systems can be nightmare. In traditional Role Based Access Control new permission requires new role and it can lead to a forest of roles in large distributed system. Within a system with hierarchical resources such a solution is more complex furthermore. With Attribute Based Access Control solution presented in this paper, there are atomic permissions (read, write, delete Architectural Component) and Access Control Policy. Hierarchical resources are managed using hierarchical attributes.

## 3. Sun's XACML API

This paper presents work with Sun's version of XACML [5]. Sun's XACML has supported only XACML 1.0 and not XACML 2.0 yet. XACML 2.0 supports Security Access Control Markup Language (SAML) protocol which is enveloping protocol and provides standardized protocol for encryption and decryption of attributes and policies on the net.
Since Sun XACML is in developing phase (toward version XACML 2.0) in order to work with it, it is necessary to download form Code Version System (CVS) (from sourceforge.net) the last version of java classes and then compile them using given build.xml file. Finally it is necessary to build jar archive using Apache's Ant tool. In that way, we can obtain the most stable version of Sun's XACML, since code for version 2.0 is added in this phase of development.

## 4. Writing XACML Policies

A policy is a Policy Set which comprises one or more policies, where a policy comprises one or more rules. There are also combining algorithms for policies and rules. For example if the combining algorithm is "ordered-permit-overrides" the firstly mentioned rules that permit access have advantage. In that case the last rule is

```
<Rule RuleId="FinaleRule" Effect="Deny"/>
```

that means that if there is not previously written permit rule access is forbidden.
There is also another case when we write as the last rule

```
<Rule RuleId="FinaleRule" Effect="Permit"/>
```

Besides Rules, a Policy comprises a Target which is necessary to find correspodent policy to the given request. A target comprises <Subject> attribute, <Resource> attribute and <Action> Attributes, where subject and resource are mandatory and action

can be <AnyAction/>. Subject attribute has to be of datatype RFC 822 (for example users.example.com), and resource attribute has to be of type <anyURI>(for example http://server.example.com).

It can be several Subject and Resource attributes in Request (besides ones that are part of Target in Policy). An example of XML segment which represents Target Resource attribute has been given as follows:

```
<Resource>
  <Resource Match MatchId=anyURI-equal>
     <AttributeValue
DataType=anyURI>http://server.example.com<AttributeValue/>
     <ResourceAttributeDesignator
DataType=anyURI
AttributeID=resource_id>
  <ResourceMatch>
<Resource>
```

It means that matching evaluation operator is anyURI-equal, that attribute is of type anyURI and that its value is http://server.example.com . Also, name of the attribute is resource_id, that is how it is compared with attributes from Request.

In a Policy a Target is followed by one or several Rules. While a target is simplified condition for access decision, the heart of most Rules is a Condition which is mostly boolean or set function. If the Condition evaluates to true, then the Rule's effect (a value of Permit or Deny that is associated with successful evaluation of the Rule) is returned. A Condition can be quite complex, built from an arbitrary nesting of non-boolean functions and attributes. The following XML segment presents a complex Condition:

```
<Condition FunctionId=string-at-least-one-member-of>
  <SubjectAttributeDesignator
    DataType=string
    AttributeId=group />
  <Apply FunctionId=string-bag>
     <AttributeValue
       DataType=string>GP<AttributeValue/>
     <AttributeValue
       DataType=string>SCP<AttributeValue/>
  </Apply>
</Condition>
```

It means that this is attribute of subject with name *group* and type *string*. Set function string-at-least-one-member-of means «at least one member of set whose elements are of type string». This segment means that attribute of subject with name group has to have at least one of given values (GP, SCP) in oder to access decision evaluates to Permit.

## 5. Working with Hierarchical Attributes

XACML has no explicit built-in support for hierarchical attributes. It is necessary to define Conditions for attributes. There are two possibilities to implement that as follows:

Lets subject's attributes hierarchy is presented on the figure 1.

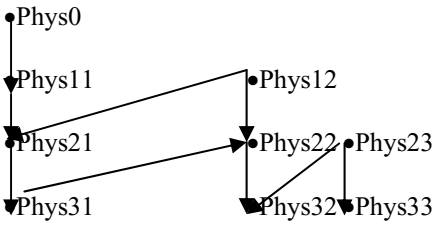


**Figure 1**. Attributes hierarchy (phys – physician in hierarchy)

First way to write Condition is as follows:

```
<Condition FunctionId=and>
<Apply FunctionId=string-equal>
 <SubjectAttributeDesignator
  DataType=string
  AttributeId=group />
   <AttributeValue
    DataType=string>Phys00<AttributeValue/>
 </Apply>
<Apply FunctionId=string-equal>
 <ResourceAttributeDesignator
  DataType=string
  AttributeId=groupr />
   <AttributeValue
    DataType=string>Phys21<AttributeValue/>
 </Apply>
</Condition>
```

It means if in Request Resource attribute with name *groupr* is *Phys21* and Subject Attribute with name *group* is *Phys00* access decision will be Permit.

To complete the Policy it is needed to write such Rules for all permited values and Policy will be ( for this example) very large – 22 pages TimesNewRoman 12 pt font. It is clear that that performances will be poor, which is indeed problem with dealing with ABAC policies in standardized languge such as XACML. Because taht it is necessary to write more compact policy with better performances.

The second way to write the Policy for our example (fig. 1.) is:

```
<Condition FunctionId=and>
<Apply FunctionId=string-at-least-one-member-of>
 <SubjectAttributeDesignator
  DataType=string
  AttributeId=group />
   <AttributeValue
    DataType=string>Phys00<AttributeValue/>
```

```
  </Apply>
  </Apply>
<Apply FunctionId=string-at-least-one-member-of>
  <ResourceAttributeDesignator
    DataType=string
    AttributeId=groupr />
    <Apply FunctionId=string-bag>
     <AttributeValue
       DataType=string>Phys11<AttributeValue/>
     <AttributeValue
       DataType=string>Phys21<AttributeValue/>
     <AttributeValue
       DataType=string>Phys31<AttributeValue/>
     <AttributeValue
       DataType=string>Phys22<AttributeValue/>
     <AttributeValue
       DataType=string>Phys32<AttributeValue/>
  </Apply>
  </Apply>
</Condition>
```

On this way written Policy has half in size and performances are 10% better. It has been written in such a way that for a subject in hierarchy for all resources down in hierarchy access is allowed.

**Table 2**. Access time for example given at figure 1. (1.7GHz processor, 512 M RAM)

| Node1 | Node2 | **T1** (ms) | **T2**(ms) | Access Decision True=Permit False=Deny |
|---|---|---|---|---|
| 00 | 11 | 2012 | 1942 | True |
| 00 | 21 | 1952 | 1843 | True |
| 00 | 31 | 1963 | 1642 | True |
| 00 | 12 | 1873 | 1682 | False |
| 00 | 22 | 1893 | 1622 | True |
| 00 | 23 | 1853 | 1662 | False |
| 00 | 33 | 1853 | 1692 | False |
| 00 | 32 | 1853 | 1622 | True |
| 11 | 21 | 1913 | 1683 | True |
| 11 | 31 | 2033 | 1682 | True |
| 11 | 12 | 1943 | 1792 | False |
| 11 | 22 | 1913 | 1642 | True |
| 11 | 32 | 1943 | 1632 | True |
| 11 | 23 | 1913 | 1652 | False |
| 11 | 33 | 1973 | 1692 | False |
| 21 | 31 | 1833 | 1672 | True |
| 21 | 12 | 1863 | 1752 | False |
| 21 | 22 | 1802 | 1763 | True |
| 21 | 32 | 1843 | 1642 | True |
| 21 | 23 | 1912 | 1633 | False |
| 21 | 33 | 1833 | 1672 | False |
| 31 | 12 | 1863 | 1633 | False |
| 31 | 22 | 1913 | 1673 | True |
| 31 | 32 | 1862 | 1753 | True |
| 31 | 23 | 1823 | 1762 | False |
| 31 | 33 | 1872 | 1663 | False |

| | | | | |
|---|---|---|---|---|
| 12 | 22 | 1852 | 1852 | True |
| 12 | 32 | 1812 | 1742 | True |
| 12 | 23 | 1963 | 1753 | False |
| 12 | 33 | 2013 | 1662 | False |
| 22 | 32 | 1833 | 1622 | True |
| 22 | 23 | 1903 | 1663 | False |
| 22 | 33 | 1853 | 1723 | false |
| 32 | 23 | 1953 | 1653 | False |
| 32 | 33 | 1843 | 1682 | False |
| 23 | 33 | 1872 | 2113 | True |
| | | Taverage=1894ms | Taverage=1698ms | |

## 6. Conclusion

This paper presents how standardized language for writing ABAC policies, requests and responses can be used in EHCR based on year 2002 CEN standard. The contribution is presentation of writing policies for hierarchical attributes. It has been presented how using set functions can improve compactness of policy and performances in the same time.

## References

[1] CEN ENV 13606 Extended Architecture, http://www.centc251.org , accessed March 2002.
[2] Joshi, J. , Bhatti, R., Bertino, E., Ghafoor, A., 2004., Access Control Language for Multidomain Environments, IEEE Internet Computing, IEEE Computer Society.
[3] Sucurovic, S., MEDIS – A Web Based Health Information System, In Proceedings of ICEIS 2006.
[4] Anderson A., A comparasion of Two Privacy Policy Languages: EPAL and XACML, http://research.sun.com/techrep/2005/smli_tr200
[5] Sun's XACML Implementation, http://sunxacml.sourceforge.net/

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# Architectural Approaches to Health Information Systems for Empowering the Subject of Care

Bernd BLOBEL [1], Peter PHAROW
*eHealth Competence Center, University of Regensburg Medical Center, Regensburg, Germany*

**Abstract.** The personal health paradigm puts the citizen in the health services business process center. This enhances the subject of care's opportunities, rights and duties regarding his/her health status and the process for maintaining and improving it. First, the citizen and his/her direct environment have to become part of the health information systems network. This implies diagnostic and therapeutic processes performed to the subject of care independent of time, location and local resources by closing the gap through appropriate mobile and miniaturized medical devices up to an implantable level. The individualization of care delivery services requires individualized diagnostic and therapeutic means based on bioinformatics and genomics methodologies. As the individual needs of a subject of care are not predictable, the system architecture must adaptively and autonomously, integrating all domains defining eHealth. Second, the architecture must be policy-controlled for empowering the subject of care, offering all privacy and security services needed. Third, embedded in the system architecture, the subject needs the knowledge presented in the right way using the right terminology to enable the intended empowerment.

**Keywords.** communication, interoperability, system architecture, policies, empowerment

## Introduction

For improving quality and safety of patients as well as efficiency and efficacy of care processes under the well known demographic, social, organizational and financial constraints, health care systems evolve towards specialization connected with decentralization and distribution. Such changes are connected to a paradigm change from organization-centered through process-controlled up to personalized care settings. Specialization and decentralization have to be combined with extended communication and cooperation for guaranteeing comprehensive care services. The aforementioned paradigms define organizational and process design, but also the architecture of supporting information and communication technology (ICT) as well as resulting ICT systems. The paper shortly introduces the paradigms, related user requirements,

[1] Corresponding Author: Bernd Blobel, PhD, Associate Professor, eHealth Competence Center, University of Regensburg Medical Center, Franz-Josef-Strauss-Allee 11, D-93053 Regensburg, Germany; Email: bernd.blobel@klinik.uni-regensburg.de; URL: http://www.ehealth-cc.de

resulting system and process design as well as communication and cooperation needs, and finally a system architecture meeting the needs and requirements.

## 1. Constraint Models of Real World Objects

For a better understanding of the paper, some definitions should be introduced first. A system (Greek: σύστημα) is the totality of related and interactive elements or components thereby forming a unit in function, objectives or purpose separated from its environment. A domain (Latin: dominium) is formed by elements or components with a common content, property or characteristic, which might be a technical, an environmental or a policy one, thereby considering a system under that domain's perspective. A system might belong to one or more domains. For simplification purposes, a system analysis should start within a single domain, afterwards combining the domains in question, however. The system components, which are derived from references by constraints and can be furthermore constrained from other domain's perspective, provide a set of functions or services.

A system or domain is separated from its environment through its boundaries clearly defining whether a component belongs to the system/domain or not. The relationships between a system as a composable/decomposable component structure of an entity and a domain as a special perspective on that entity have been introduced as two dimensions of the Generic Component Model (GCM) for formally describing real world entities. The unified development process defines the third dimension of the model (Figure 1) [1]. By this way, a multi-model approach to any kind of systems ranging from information systems over legal/organizational up to living ones has been developed and deployed, enabling system analysis, design, implementation and maintenance. Following, policies in a system's architecture context will be shortly discussed.

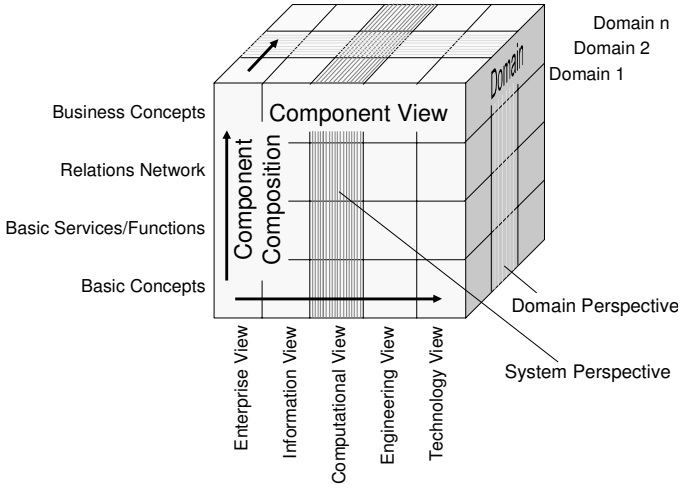


**Figure 1.** The Generic Component Model [1]

A system is characterized by its structure and its behavior. The system's components and their arrangements define its structure. The components' operations (functions) and interrelationships define its behavior. If we declare a policy as set of legal, regulatory, organizational, social, functional and technical constraints on a system, the system's specialization (constraints) from a generic reference resulting in a specific system structure and behavior is strongly influenced by the policy ruling this system's design and deployment. In other words, the policy domain defines constraints on other domains. While a system architecture is described by the system's components, their functions and their interrelationships, the policy is the plan for designing, implementing and deploying a system's architecture.

## 2. Health Care Paradigm, Communication and Cooperation Requirements and Interoperability Levels

### *2.1. Information Cycle*

Communication and cooperation is performed to meet certain objectives such as maintaining or improving health conditions and status. In that context, two or more actors share information about a real object of common interest and collaboratively act on that object. Reality is typically described by simplified and simplifying models reflecting intentions and interests of the person creating and using the information. In the information cycle, the observed data is being interpreted according to intended objectives to perform the right actions for achieving those objectives. Both steps require knowledge of experts operating in the domain of interest. Checking the activity's outcome, the cycle starts again. The information cycle is represented in the different information definitions provided by C. E. Shannon, L.-M. Brillouin, and N. Wiener.

### *2.2. Interoperability Levels*

Communication and cooperation can be performed at different level of interoperability. Here, technical interoperability, structural interoperability, syntactic interoperability, semantic interoperability, and service-oriented interoperability can be distinguished. While technical interoperability establishes harmonization at the plug&play, signal, and protocol level, structural interoperability is based on exchange of agreed data, syntactic interoperability provides harmonized messaging and document exchange. Semantic interoperability requires harmonized information model based on common references and agreed ontology-based terminology. The higher level of semantic interoperability - service-oriented interoperability- is realized through invocation of services accessed via standardized interfaces. Thereby, common business models are needed. Interoperability levels reflect information cycle aspects. While communication focuses on exchange of meaningful and correctly interpreted messages, cooperation depends on the applications' behavior and functionalities, defined by their structural components, their functions and the components' interrelationships. Therefore, applications' behavior and functionalities is defined by the application architecture. The assessment of systems regarding their interoperability has to be provided by analyzing their architecture and the completeness of the information cycle [2].

### 2.3. Healthcare Paradigms

An organization-centered health system is characterized by a more or less complex policy separating it from another system. The policy comprises the legislation and regulations followed, as well as organizational and functional constraints applied. Within this policy domain, processes and workflows, concepts and knowledge, knowledge representation as well as decision support deployed including preferred terminologies and ontologies, but also infrastructural services have been harmonized. By that way, the components establish closely coupled subsystems for enabling interoperability (Figure 2). Because of the common framework established, simpler communication protocols at the level of syntactic interoperability can be deployed (without communicating underlying concepts, policies, etc.) for successfully realizing communications and co-operations. Here, HL7 v2 could be named. There is no or weak communication between different healthcare establishments, mostly based on doctor's reports on paper or electronically. Bringing the latter together would allow for a rudimentary electronic health record. In summary, the caring organization defines the process.

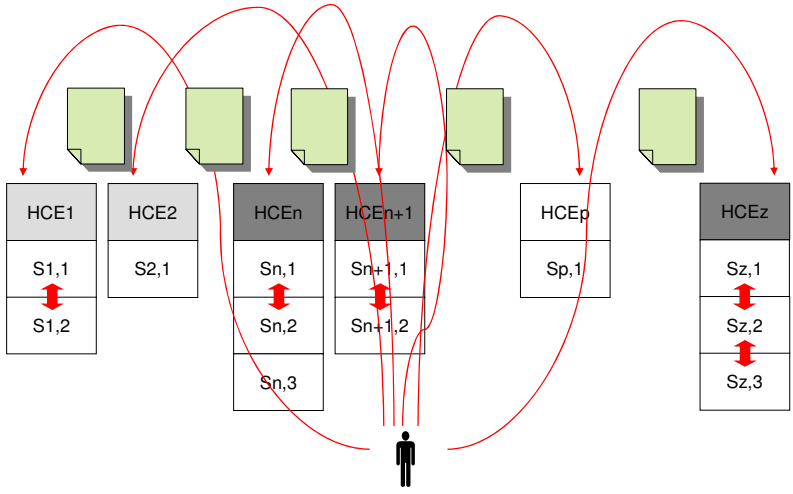


**Figure 2.** Organization-centered care paradigm

Following the shared care paradigm, disease-specific policies, workflows, concept representation, terminologies and underlying ontologies have been harmonized between different healthcare establishments enabling specialization and decentralization for improving quality of patient's care as well as efficiency and efficacy of health delivery processes. As the communication and cooperation between organizations including their underlying and supporting health information systems are based on different policies, workflows, concept representation, terminologies and underlying ontologies, information commonly needed has to be communicated, forming loosely coupled systems. Technical means for providing interoperability are standardization, mapping, adaptation, etc. of models, protocols, tools and infrastructures commonly used (Figure 3). Despite all harmonization efforts provided,

communication and cooperation between different organizational and technology domains requires communication protocols for semantic interoperability such as HL7 v3 and similar protocols named in the figure. The caring persons and or disease management controller define the process.

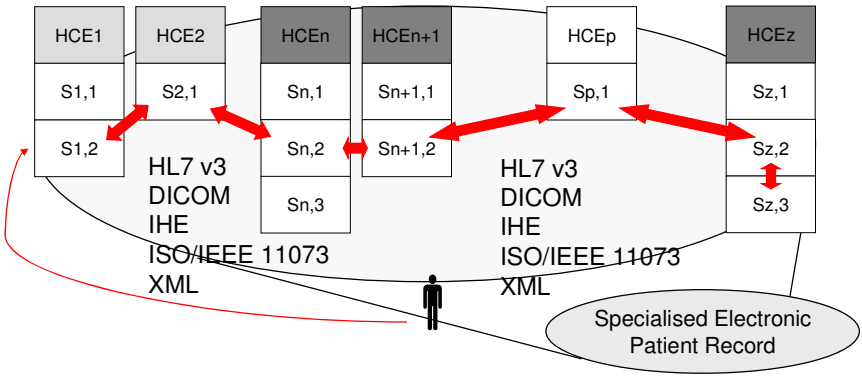


**Figure 3.** Shared care paradigm

Personalization of health services puts the patient or -in the case of including prevention, elderly care, social services, etc.- the citizen before becoming a patient in the business process center [3] (Figure 4).

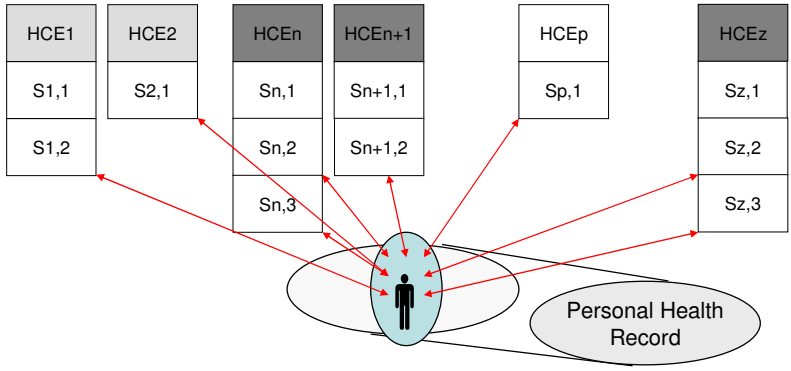


**Figure 4.** Personal health paradigm

As the process of diagnosis and therapy becomes independent of localization, time and local resources, the informational gap between the different actors must be closed making the patient/citizen part of the information network. The patient/citizen status, his/her needs, but also his/her intentions and wishes define the process. In such an environment, only frameworks (legislations, general policies, ethical principles), basic knowledge, and existing infrastructures, but no policy, processes and workflows, special concepts and knowledge, knowledge representation as well as decision support deployed including preferred terminologies and ontologies can be pre-defined and

harmonized. Even the application's functionality requirements are unpredictable und has to be adaptively designed and implemented at runtime.

## 3. Computing Paradigms for Supporting Ubiquitous Care

For managing the aforementioned requirements, ubiquitous health services based on the ubiquitous computing paradigm have to be provided. As the subject of care is in the health services business process center being served independent of time, location, and local resources, he/she has to become integrated part of the health information systems network. This implies communication facilities, diagnostics and therapeutic means, as well as the entire infrastructure needed in the care delivery process. Therefore, mobile computing, which is widespread in all industrial countries and increasingly also in developing countries, must be combined with pervasive computing integrating biomedical engineering, telematics, informatics, bioinformatics, and medicine, and finally with autonomic computing enabling adaptive, self organizing systems as shown in Figure 5. For more information see [2].

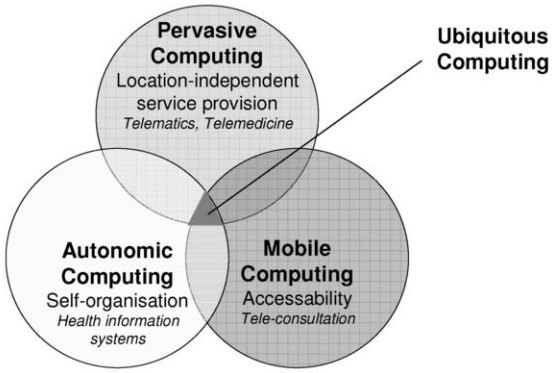


**Figure 5.** Computing paradigms to be met for ubiquitous care delivery

## 4. Architectural Paradigms for Personal Health Information Systems

For providing advanced and sustainable communication and cooperation, architectures for personal health information systems have to be open, scalable, flexible, portable, distributed, standard-conformingly, semantically interoperable, service-oriented, user-accepted, trustworthy and lawful. Therefore, the architectural paradigms presented in Table 1 have to be met:

**Table 1.** Architectural paradigms for realizing the addressed system characteristics

| Architectural Paradigm | Supported Characteristics |
|---|---|
| Distribution | Interoperability |
| Component-orientation | Flexibility, scalability |
| Model-driven, service-oriented design, considering concepts, context and knowledge | User acceptance, lawfulness |
| Comprehensive business modeling | User acceptance, lawfulness |
| separation of platform-independent and platform-specific modeling (separation of logical and technological view) | Portability |
| Specification of reference and domain models at meta-level | Semantic interoperability |
| Agreed reference terminologies and ontologies | Semantic interoperability |
| Unified development process | Semantic interoperability |
| Performance, User friendliness | User acceptance |
| Embedding services in the architecture (including advanced security and privacy services) | User acceptance, lawfulness |

## 5. Personal Health Information Systems' Architectural Requirements to Support Subject of Care Empowerment

For supporting the subject of care empowerment through personal health information systems, the system's architectural components, their interrelationships as well as their unified development process have to be appropriately profiled, following corresponding policies and constraints. These special profiles also apply to the corresponding concepts representation and the ontology-based terminologies used. As different domains are involved, different ontologies have to be mapped using reference ontologies [4]. Following, the essential architectural solutions including infrastructural services will be discussed shortly.

### *5.1. Component Structure and Composition*

The architecture has to be based on formal concepts and rules, managed in knowledge bases and designed and implemented at runtime autonomously. As user needs, expectations, education, training and proficiency are individual, structure and behavior of components including their composition have to be user-definable. The definition must be supported by appropriate tooling. It should be rule-based as well as reflect and interpret user intentions. For that reason, the system has to be decomposed up to its basic concepts, thereby enabling the scalability and flexibility required as well as for supporting corresponding interactive features.

### *5.2. Concept and Knowledge Representation*

Modeling concepts in a system's architecture context requires knowledge and creates knowledge [5]. Thereby, concepts represent the architectural basic components and their composition, so defining (and constraining) any system architecture. As concepts derive from the business domains and are only formally represented in information systems, the creation and maintenance of concepts and knowledge are rights and duties of domain experts and not of informaticians or computer scientists, as frequently wrongly done in the past and thereby minimizing the user acceptance of the resulting solutions. This requires the separation of concept/knowledge creation from its informational implementation, the acceptance of different domain languages and their transformation in formal (modeling) languages (meta-languages), appropriate tooling

and infrastructural services, which must be supported by the process and system design. In personal health setting, the subject of care has to be carefully included and served in this perspective.

Another challenge regarding concept and knowledge representation arises from the multi-disciplinary (medicine, informatics, telematics, biomedical engineering, bioinformatics, genomics, jurisprudence, economy, etc.) and therefore multi-media approach (text, graphics, signals, images, gestures, etc.) of personal health. The availability of knowledge and appropriate knowledge representation depends on the educational level as well as on the cultural and the social environment. Therefore, education is a human obligation, covering the different social groups in a society and nowadays the relationships between industrialized and developing countries. Approaches such as patient/citizen information systems, portals, user-friendly solutions, but also health academies, WHO activities, the work of the Open Source Community, and others are promising initiatives to overcome digital and social divide. However, the quality of information distributed by dubious sources via the Internet must be watched very carefully, as they could provide health risks and harm instead of benefits.

### *5.3. Terminology and Ontology*

Based on different knowledge, training, and experiences, but also business processes they are related to and motivations and intentions they are following, different user groups will apply different terminologies which are frequently based on different ontologies as well. This implies that the infrastructural service Terminology Service has to manage and to map different terminologies. For adequately binding different concepts from different domains in the context of multi-purpose use of information, ontologies must be mapped through a reference ontology. Even within one complex domain like medicine, different ontologies for health have been developed such as UMLS, SNOMED, Read Codes, etc., according to different intended purpose. Different ontologies of a domain are interrelated.

Using a computation-independent approach, the domain knowledge for performing a specific business has to be represented defining Business Domain, Business Process, Location, Business Organization, Event, and Business Motivation regarding meta-models, concepts and relationships. Regarding ontologies and ontology representation languages, the Open Biomedical Ontologies (OBO) Foundry initiative must be mentioned here. However, there are more examples for advanced ontologies available [6].

Appropriate terminology and ontology services provide an essential prerequisite for patient's/citizen's empowerment.

### *5.4. Policy Management*

Policies define important constraints for design, implementation and deployment of personal health information systems. Therefore, the policy domain is an important constituent of personal health information systems architectures as defined in the GCM. As a consequence, policies have to be embedded into the architectural components, defining and constraining their structure and behavior as well as their interrelationships in the context of compositions/decompositions.

In essence, policy management is crucial service especially empowering the policy manager. In the completely distributed, unpredictable and open environment of

personal health settings, the establishment of trusted authorities for managing security and privacy does not work anymore. Therefore, the subject of care has to be the main policy manager thereby empowering him//her as required according to many countries' legislation. Policy management has to be performed dynamically. The realization of distributed policy management facilities is excellently supported by the GCM architecture approach. Following, we will be focused on the security and privacy aspect of policies.

While different aspects of security and privacy have to be considered such as legal/political, organizational and technical ones, the technical issues are frequently the minor challenges. As not everything in the security and privacy domain with its complexity and diversity especially in the healthcare arena can be ruled, cultural and ethical principles must be set. For that purpose, Fair Information Principles and Ethical Principles have been defined by *Kluge* on behalf of the International Association for Medical Informatics and have been adopted by the World Health Organization. Fair Information Principles concern openness and publicity, limitation of data collection, limitation of information disclosure, limitation of information use, security, access control, while Ethical Principles challenge autonomy and respect of person, exclusion of impossibility for realizing the right, exclusion of relevant differences between right and realization (praxis), obligation for best action, assurance of range of priority (logic, natural, voluntary), assurance of equality and legality [7].

### *5.5. Auditability and Traceability of Status and Actions*

A basic legal requirement for ensuring that policies, regulations, principles have been met is the auditability and traceability of status and actions of all principals involved. Here, the Object Management Group (OMG) definition of principals (person, organization, system, device, application, component) as actor in an communication and collaboration process must be used. By that way, the advanced interoperability approach in personal health setting providing ubiquitous care can be reflected properly.

### *5.6. Interoperability Levels*

As already mentioned above, the level of commonalities in policies, knowledge, process design, terminology, ontology, etc., defines the required level of interoperability. For device communication within one laboratory, simple data exchange might be sufficiently, while in home care and elderly care service level interoperability has to be guaranteed. While a high level of interoperability empowers the subject of care in comprehensively using health services, his/her intervention opportunities are frequently decreasing. For solving this problem, the granularity of service components has to be sufficient enabling appropriate and free selection services or objects. This architectural principle is closely connected to the aspects of system design and knowledge/concept representation.

### *5.7. Quality Assurance*

The challenge for better health to all in general and in personal health especially can only be met, if the quality of information and informational processes is improving. In that context, quality problems of information distributed by dubious sources via the Internet and possibly providing harm instead of benefits have to be mentioned again.

The Institute of Medicine reports assessing the number of deaths caused by information errors to 40,000 – 96,000 a year clearly demonstrate the potential in this field [8]. These circumstances also caused the move of Standards Developing Organizations (SDOs) in the Health Informatics domain (ISO TC 215, CEN TC 251) towards safety-related new work items.

Testing, quality labeling and certification of personal health information systems and components is an essential requirement, which increasingly concerns SDOs (e.g. HL7 [9]), governmental institutions (e.g. CCHIT [10]), international institutions (e.g. EuroRec Institute [11]), projects (e.g. Q-REC [12]), etc.

### *5.8. Infrastructural Services*

The implementation of health information systems empowering the patient or the citizen respectively requires a set of infrastructural services supporting the user community or facilitating system performance. Here, register services, data management services, replication services, normalization services, message services such as transformation services, routing services, encoding and decoding services, parsing services, serializing services, protocol services, indexing services, integration services such as catalogue services, broker services, mapping services, queuing services, interoperability services such as search and resolution services, business components such as business rules services, orchestration services, assembly services, common services such as auditing, log management and exception/error handling services, data security and privacy services such as Trusted Third Party services, anonymization, pseudonymization, and many other must be designed, implemented and maintained.

### *5.9. Usability and User Acceptance*

Supporting the business objectives of user domains, design, implementation, and deployment of personal health information systems components and functionalities has to be evaluated from the end user's perspective, but not from a developer's viewpoint. In that context, user needs, user expectations, user intentions, the performance of the application as well as user friendliness and usability are important criteria for assessing and improving systems structure and behavior. Important aspects to be considered are the level of knowledge, the access features, the advocacy, the way of decision making, the health status and the expected outcomes respectively, and the literacy. For more details see [13]. Regarding usability and user acceptance, important work has been provided by the EFMI Working Group "Assessment of Health Information Systems" [14]. This includes the related paper in this volume [15].

## 6. Discussion

Nowadays, most of the existing health information systems do not allow for patient involvement and patient empowerment. In that context, both hospital information systems and physician's office systems have to be mentioned not being able to provide patients access to their personal health information. This holds for local access at the system's site as well as for remote access from the patient's/citizen's home.

As first step into the direction of patient involvement and of realizing the patient's ownership on his/her information as required in some European country's legislation, some healthcare establishments hand over doctor's reports, diagnostics images and other document either as paper or as electronic file. And even electronic communication between patient and health professionals is evolving step by step.

Several countries aim at an infrastructure based on electronic health cards (eHC) assigned to patients/citizens. Such patient "owned" carrier (in Germany e.g., this card is strictly speaking owned by the card issuing insurance company) bears the card holder's personal information, insurance data including an electronic European Health Insurance Card (eEHIC), the electronic prescription, and security services such as strong authentication and digital signature as compulsory functions, but also a medication file and an electronic health records at rudimentary level, and some others functions to be voluntarily used depending on the card holder's consent. At a future implementation level establishing medication files or more comprehensive EHRs on networks, eHC or also eEHICs with lower functionality can be used as secure user assigned tokens to the network [13, 16].

In a personal health environment, which includes actors without special legal obligations, ethical rules (Hippocratic Oath) or other constraints, the subject of care (patient or citizen) has to play an active role. This requires a new type of health information systems based on an architecture described in this paper. Business requirements and user needs have to define the solution. Knowledge in research and development of such kind of approaches is not yet well developed. However, some big players in the health informatics and eHealth field are currently preparing themselves for meeting the challenges mentioned in this contribution. The eHealth Competence Center Regensburg essentially contributes in this development by organizing international tutorials and seminars, preparing an advanced International Master Course "International Master in eHealth" and collaborating with industry and governments in the field of sustainable eHealth solutions including security, privacy, safety and subject of care empowerment.

## 7. Conclusions

Contrary to currently applied health paradigms where the organization of health delivery processes and patient empowerment are not in line, personal health paradigm and patient empowerment are completely aligned. Personal health system architectures putting the patient/citizen in the business process center are based on design principles, functionality and infrastructural services "automatically" empowering the subject of care. Technology is a minor aspect in that context. Organizational, social, and ethical implications are more important on the one hand, but more challenging to be established on the other hand. Considering a system's architecture from a comprehensive view, constraints defining a system's structure and behavior (functionality) not only act within a domain but also between domains. Therefore, advanced, sustainable pHealth systems have to follow the GCM approach completely reflecting the multi-domain dimension of real world systems [5].

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## References

[1] Blobel B. Educational Challenge of Health Information Systems' Interoperability. Methods Inf Med 2007; 46: pp. 52-56.
[2] Blobel B. Introduction into Advanced eHealth – The Personal Health Challenge. In: Blobel B, Pharow P, Nerlich M (Edrs.): eHealth: Combining Health Telematics, Telemedicine, Biomedical Engineering and Bioinformatics to the Edge - Global Experts Summit Textbook. Series "Studies in Health Technology and Informatics", Vol. 134. IOS Press, Amsterdam, Berlin, New York, Tokyo; 2008, pp. 3-14.
[3] Blobel BGME, Pharow P, Norgall T (2007) How to Enhance Integrated Care towards the Personal Health Paradigm? In: Kuhn KA, Warren JR, Leong T-Z (Edrs.): MEDINFO 2007. IOS Press Amsterdam, Berlin, Oxford, Tokyo, Washington, DC; 2007, pp. 172-176.
[4] Blobel B. Concept Representation in Health Informatics for Enabling Intelligent Architectures. In: Hasman A, Haux R, van der Lei J, De Clercq E, Roger-France F (Edrs.): Ubiquity: Technology for Better Health in Aging Societies. Series Studies in Health Technology and Informatics, Vol. 124. IOS Press, Amsterdam; 2006, pp. 285-291.
[5] Blobel B, López DM, Pharow P. Model-Driven Design of an Advanced EHR Infrastructure. Meth Inf Med (submitted)
[6] Smith B, Brochhausen M. Establishing and Harmonizing Ontologies. In: Blobel B, Pharow P, Nerlich M (Edrs.) eHealth: Combining Health Telematics, Telemedicine, Biomedical Engineering and Bioinformatics to the Edge - Global Experts Summit Textbook. Series "Studies in Health Technology and Informatics", Vol. 134. IOS Press, Amsterdam, Berlin, New York, Tokyo; 2008. p. 219-234
[7] IMIA Code of Ethics for Health Informatics Professionals. http://www.imia.org/code_of_ethics.html
[8] Kohn LT, Corrigan JM, and Donaldson MS (Edrs.) Building a Safer Health System. Committee on Quality of Health Care in America. Institute of Medicine. National Academy Press, Washington, D.C.; 2000
[9] Health Level 7, Inc.: http://www.hl7.org
[10] Certification Commission for Health IT: http://www.cchit.org
[11] EuroRec Institute: http://www.eurorec.org
[12] European Quality Labelling and Certification of Electronic Health Record systems (EHRs) (Q-REC) (see EuroRec Institute)
[13] Pharow P, Hildebrand C, Blobel B: The Changing Role of Patient and their Health Cards in Integrated eHealth Environments. In: Reichert A, Mihalas G, Stoicu-Tivadar L, Schulz S, Engelbrecht R (Edrs.): Integrating Biomedical Information: From eCell to ePatient, pp. 70-74. IOS Press and Akademische Verlagsgesellschaft Aka GmbH, Berlin; 2006.
[14] European Federation for Medical Informatics: http://www.efmi.org
[15] Nykänen P. Requirements for User-Friendly Personal Health Information Systems. In this volume.
[16] Blobel B, Pharow P (2005) Patient Data to Go – Germany's National Smart Card Project. Journal of AHIMA/February 2005 – 76/2, pp. 49-51.

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# Requirements for User-Friendly Personal Health Information Systems

Pirkko NYKÄNEN [1]
*University of Tampere, Department of Computer Sciences, Finland*

**Abstract.** This paper presents background of personal health systems research and analyses requirements for personal health systems from various perspectives. The analysis shows that social and contextual aspects of personal health systems need more attention in the future and that systems development should not be technology-driven but driven by user needs and use contexts.

**Keywords.** eHealth, personal health systems, user

## Introduction

eHealth refers to the use of ICT to improve or enable health and healthcare [1,2]. eHealth conceptualization broadens the scope of healthcare delivery; citizens are placed in the center of services, services are in many situations offered to be used through the Internet e.g. at home and citizens can have interaction with health professionals who look after their health needs.

eHealth is expected to contribute to development of new ways of delivering health services and to impact on the organization and structure of the healthcare delivery system [3, 4]. eHealth is not only of technological improvement but it is of reengineering of healthcare processes, and of consideration of the socio-technical aspects of design and development of applications. Many studies identify the promises of eHealth to be in the manner and degree to which eHealth can build on the advances in ICT to support the development of the healthcare infrastructure [3, 5]. Healthcare services are expected to be better accessible and data available any place and any time independent on where data is stored or created.

Personal health information systems are eHealth solutions that place the individual citizen in the center of the healthcare delivery process. Personal health systems may be seen as an important component to bring continuity of care by extending care to ordinary living environments and even to citizens on-move, and to assist the shift towards preventive, personalized, and citizen-centered care [6, 7].

Current paradigm applied in healthcare service provision and delivery is the hospital-centered care model. Paradigmatic change to citizen-centered care model enables and supports patient and citizen to be actively involved in his/her prevention and care process, throughout his/her life, anytime and anywhere [6, 7, 8, 9]. The real implementation of citizen-centered care model requires, however, overcoming of

[1] Corresponding author: University of Tampere, Department of Computer Sciences, PO Box 607, 33014 University of Tampere, Finland, E-mail: Pirkko.Nykanen@uta.fi

technological and societal obstacles. Currently, certain technologies are available, while social aspects related to the personal health information systems need to be taken carefully into account. These societal issues cover e.g. conceptualization of personalized healthcare and the socio-technical contexts of healthcare service provision and use [7, 10, 11, 12].

## 1. Background of Personal Health Information Systems Research

Research on personal health systems started in EU FP5 with emphasis on the development of technologies and communications infrastructure to support delivery of healthcare at the point of need. It continued in FP6 with focus on integrated systems and services and also on the personalization of health systems and care. Many prototypical systems and devices have been developed in this research to support citizen-centered care [3, 6, 7]. Current FP7 defines personal health systems (PHS) as systems that cover a wide range of systems including wearable, implantable or portable systems, as well as point-of-care diagnostic devices [7]. The functioning of PHS is related to three blocks: 1) Acquisition of data and information, 2) data processing and analysis on what is clinically relevant, and 3) communication from patient to doctor/hospital, and to patient (e.g., treatment and guidance). These blocks are interconnected, and the links between them are of as equal importance as the blocks themselves [3, 6, 7].

In current PHS research management of chronic diseases is seen to be a major issue, taking into account (i) the increasing burden which chronic diseases impose on healthcare systems in terms of human and financial resources, (ii) the demographic problem of ageing population, but also (iii) the potential for development of a market for new personalized care solutions [6, 7].

The vast number of websites dedicated today to offer health advice and health related information to citizens grows in the Internet and increases the need to protect the citizen from poor quality and incorrect information and to have standards of conduct that protect the interests of the citizen [13]. The number of citizens who access health and treatment information through Internet is growing [14, 15, 16]. This fact is opening up opportunities for new eHealth consumerism characterized by five converging drivers: Financial responsibility, public policy, comparative quality indicators, connectivity and social/demographic changes. Consumers are finding themselves empowered to acquire more health services in terms of information and value-added services, such as convenience, well-being or satisfying individual preferences [15, 16, 17, 18, 19].

## 2. Requirements for Personal Health Information Systems

The health environment sets special requirements for personal health systems, especially in relation to confidentiality and security of personal health related data. The health context is very sensitive, citizens and health professionals have to take into account the nature of data and information and the sensitivity of the context where data is acquired and managed [12].

Personal eHealth systems are used in various use contexts and users differ in user profiles and in characteristics of use. These need to be mapped to the personal health

system qualities. Also the personal health systems differ in system type; they may be wearable, embedded with equipment or accessed and used through the Internet.

The purpose of personal eHealth systems is to support and help citizens and patients to take care of their health and wellness, to empower them with reliable and personalized knowledge and information, to help them to maintain their health status, and to support them in prevention of diseases and in adoption of healthy lifestyle.

Citizens are today well informed on various possibilities and want to be active participants in their healthcare processes. Through participation they want to improve their health status and to have personalized services and advice on their personal health situation. While taking part in their own health-related processes citizens come from varying situations [14]:

- Healthy individuals, who want to assess their health status related to prevention and to evaluate their personal risk factors:
    - They may need professional advice to adopt a healthier lifestyle,
    - They wish to maintain their health status,
    - They want to follow specific programs, e.g. dietary programs, to prevent potential health problems,
    - They need specific monitoring because of a specific health situation,
    - They live with a person with risk factors of some kind.
- Individuals with ascertained risk factors:
    - They need professional advice to reduce or control the risk,
    - They need monitoring of their attempts to control the risk factors.
- Individuals with diagnosed disease or other problematic situation:
    - They need information and/or professional advice to prevent potential problems and to maintain or improve their current health situation,
    - They need continuous monitoring of their health status and information on detected changes, problems or means to improve their situation.

The requirements for personal eHealth system should cover from the technological dimension at least the following:

- Dynamic creation of user profiles with the capacity to relate the domain of care with personal preferences and needs. This is needed because the global access to information on care and preventive information raises significant risks for end users who do not have the tools to extract valuable information from that available and of real relevance for their personal health treatment needs.
- Knowledge management and sharing is the key issue in the modern eHealth care models.
- The integrity of data in multi-user environments as well as ensuring accountability of actions is essential for patient safety. The trust aspect in healthcare professional-citizen /patient linkage is critical and is influenced by the discontinuity of information flow that exists outside the controlled healthcare environment.

In addition to these technological aspects the societal acceptance of eHealth systems is crucial. We need to consider how to enhance and evaluate uptake of new services considering that citizen's experience with service improvements elsewhere will drive bigger expectations and demands in eHealth. Collection of personal information, including health related information, has the risk of being misused by employers, health plans and others to discriminate based on health status and profiles.

The shift from organization-centered care model to the citizen-centered care model puts the focus on the citizen and his/her needs, and therefore we can derive, based on

literature [7, 8, 9, 10, 11, 12, 17, 19, 20], the basic requirements for personal eHealth systems:

- Care is based on continuous relationships: Citizens receive care whenever they need it and in many forms.
- Personalization of services is based on citizens' needs and values. The healthcare system is able to respond to individual choices and preferences.
- Citizens are given the necessary information and the opportunity to exercise the degree of control they choose over healthcare decisions that affect them.
- Citizens have full access to their own medical information and to clinical knowledge.
- Citizens receive care based on the best available scientific knowledge.
- Citizens are safe from injure caused by the care system.
- The healthcare system makes information available to patients / citizens and their families that allow them to make informed decision when selecting of a health plan and therapy strategy.
- The health system anticipates citizens' needs, rather than simply reacts to events.

A citizen-centered personal health system environment should be able to provide:

- Healthy life style information that is adapted to the citizen's individual profile: needs, preferences, context, behavior and health status and profile.
- Secure, pervasive, wireless access to services that permit an easy, friendly interaction to requested information and updating of personal data.
- Monitoring services and tools to help citizens / patients in understanding and fulfilling of life style recommendations.
- Individual-context oriented support on the use of biomedical devices for data capture and transmission to healthcare organizations from any place where the patient is located.
- Higher accuracy, precision, sensitivity and specificity for the personalized diagnostic and therapy recommendations and avoidance of information overload, false alarms, false positive and false negative recommendations, more intelligence and security from a privacy point of view.

## 3. Important Issues in Implementation of Personal eHealth Systems

To implement citizen-centered care model and a personal eHealth environment we need to conceptualize the services meaning that the services are specified in terms on service ontologies that explicitly specify the citizen-centered sustainable and personalized healthcare services in the context. On the basis of these conceptualizations user scenarios can be outlined and presented to describe the use and usage situations: Citizen as a care provider, citizen as a main driving force for selection of health scenarios, citizen health profiles and personal health status as core elements of the conceptualization. From these scenarios we can proceed to implementation; certain technologies are available, or will be available in a short time, and implementation should not be technology-driven, but driven by societal and contextual issues.

During the Personal Health Systems consultation workshop [7] the following issues were raised to be considered for better implementation and exploitation of personal health systems:

1. Evaluation and validation: Any new solution developed needs evaluation, and possibly validation, implying as a minimum the proof-of-concept in the use setting. This means that we need to demonstrate, even with a small group of users, that the new solution is technically valid, safe to use and efficient, and that it is useful for the user and has positive effect on therapy, disease management or prevention. In addition, usability should be studied to ascertain that developed solutions are user-friendly and easy-to-use. We need to apply robust evaluation and measurement methodologies that can prove the positive benefits of eHealth systems.
2. Stakeholders' involvement: In a research project that develops an eHealth solution it is difficult to push the results to the market if there are not enough users involved or if the users are not enough experienced and confident in the solution. It would help to have brainstorming sessions closer to the physicians, and in order to get the most out of the sessions, they should be well planned and focused.
3. Business models: They are essential to support the financially sustainable exploitation of project results. This is particularly urgent for chronic disease management and early prevention applications. These are not yet easily defined as the healthcare is very organization-centered still today and not that much focused on home care or personal eHealth systems. The business models should have clear incentives to attract investments from industrial players.

## 4. Discussion

Development and use of personal eHealth systems will help citizens take better care of their own health, to be active in prevention and in adoption of healthy lifestyle as they are supported by personal tools and reliable, focused information and knowledge that are targeted to their own needs and requirements. From the healthcare delivery system viewpoint personal health systems are expected to improve the efficiency and effectiveness and reduce costs, because it is realistic to expect that wide application and use of these systems will reduce hospital stays and help citizens to be involved in their working life longer and in better condition. Special benefits from these systems can be seen for citizens with chronic diseases, because they can be supported with different systems to take measurements at home.

Currently we are not yet at this phase with personal eHealth systems because many existing systems are still prototypical, expensive, too complicated technology and not user-friendly for citizens, especially not for elderly citizens.

It is possible to overcome these barriers by putting the citizen into the center of the development of personal eHealth systems. We need to start with the users' needs and requirements, conceptualization of the personalized healthcare with the citizen in focus, and considering the socio-technical context of the service provision and use. Technologies should not determine what we are developing, but the citizens' needs and the use and user contexts should be the determinants for the development.

From this perspective a lot of potential exists in developing systems for intelligent decision support, which integrate and process multi-parametric data. When talking about measurements and diagnosis, it is important to know under which conditions the diagnosis was made and how the measurements were taken, this calls for context awareness in systems [7].

From the issues presented we find that much attention is needed in near future with these personal eHealth systems to safety, security, privacy and confidentiality issues in a multi-user, multi-application environment, and to ontologies and information models, and to interoperability of heterogeneous data sources, and to evaluation in terms of usability, usefulness, effects and impacts.

## References

[1] Silber D. The case for eHealth. European Commission, Information Society, eHealth Conference 2003, European Commission.
[2] Eysenbach G. What is e-health? Editorial. J Med Internet Res 1(2), 2001, e20.
[3] Iakovidis I, Wilson P and Healy JC. eHealth. Current situation and examples of implemented and beneficial e-health applications. IOS Press, Studies in Health Technology and Informatics, Amsterdam, The Netherlands, 2004.
[4] Wilson P, Leitner C and Moussalli A. Mapping the potential of eHealth. Empowering the citizen through eHealth tools and services. eHealth Conference 2004. European Institute for Public Administration. Maastricht, The Netherlands.
[5] Nykänen P. eHealth systems, their use and visions for the future. In: Schuring RW and Spil TAM (eds.), eHealth systems diffusion and use: The innovation, the user and the use IT model. Idea Group Publishing, Hershey, USA, 2005, 281-293
[6] Conference on "Personal Health Systems: Deployment opportunities and ICT research challenges". ec.europa.eu/information_society, retrieved 10.4.2008
[7] Personal Health Systems Consultation workshop , January 2008, Tampere, http://www.ehealthnews.eu, retrieved 5.4.2008
[8] Demiris G, Afrin LB, Speedie S, Courtney KL, Sondhi M, Vimarlund V, Lovis C, Goossen W, Lynch CL. Patient-centered Applications: Use of Information Technology to Promote Disease Management and Wellness. A White Paper by the AMIA Knowledge in Motion Working Group, J Am Med Inform Assoc. 2008;15:8 –13
[9] Halamka JD, Mandl KD, and Tang PC. Early experiences with personal health records. J Am Med Inform Assoc. 2008;15:1–7.
[10] Iakovidis I. Towards personal health record: current situation, obstacles and trends in implementation of electronic health care record in Europe. Int J Medical Informatics 52 (1998), 105-115
[11] Berg M. Patient care information systems and health care work: A socio-technical approach. Int J Medical Informatics 55, 1999, 87-101
[12] e-Health - making healthcare better for European citizens: An action plan for a European e-Health area, Commission of the European Communities. COM (2004) 356, Brussels.
[13] Wilson P. How to find the good and avoid the bad or ugly: a short guide to tools for rating quality and health information on the Internet. BMJ 9 (324), 2002, 598-602
[14] Spink A, Yang Y, Jansen J, Nykänen P, Lorence D, Ozmutlu S and Ozmutlu HC. A study of medical and health queries to web search engines. Health Information and Libraries Journal 21, 2004, 44-51
[15] Budtz S and Witt K. Consulting the Internet before visit to general practice. Patients' use of the Internet and other sources of health information. Scan J Primary Health Care 20(3), 2002, 174-176.
[16] Fallis D and Fricke M. Indicators of accuracy of consumer health information on the Internet: a study of indicators relating to information for managing fever in children at home. JAMIA 9(1), 2002, 73-79.
[17] Gerber BS and Eiser AR. The patient-physician relationship in the Internet age: Future prospects and the research agenda. J Med Internet Res 3(2), 2001, e15.
[18] Gruen J. The Physician and the Internet: Observer or participant? MD Comput 16(6), 1999, 46-48.
[19] Jones R, Balfour F, Gillies M, Stobo D, Cawsey AJ and Donaldson K. The accessibility of computer-based health information for patients: Kiosks and the Web. Medical Information 10, 2001, 1469-73.
[20] Potts HWW and Wyatt JC. Survey of doctors' experience of patients using the Internet J Med Internet Res 4(1), 2002, e5.

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# Changes in Doctor-Patient Relationships for Realizing the Personal Health Paradigm

Heather GRAIN [1]
*Llewelyn Grain Informatics and China Health Program, School of Public Health, La Trobe University, Melbourne, Australia*

**Abstract**. Doctors and patients have different expectations of their relationship with each other. Doctors are struggling with changes in expectations without changes in education or health care system delivery, while patients have significantly more information available to them, and expectations of the health system and their doctor that often does not match what the system is able to provide to them. This paper identifies the major issues for each group and the impact of these issues as they affect the patient-doctor relationship.

**Keywords** patient-doctor relationship, consumer health, health record systems

## Introduction

Traditional health care was undertaken in an environment where the doctor had the knowledge and the patient was dependant, often desperately so, upon that doctor's knowledge and skill for relief and treatment of their ills. This situation resulted in a subservient patient and a paternalistic or occasionally worse, a dictatorial doctor.

This paper represents the observations of doctor-patient relationships in the EHR environment in Australia, takes into account input from the health consumer movement, including specific instances cited at meetings of the Consumer health Forum Australia and the contrasts between the perspectives of doctors and patients as a group.

## 1. The Background of the Relationship

### *1.1. Clinical World Changes*

We are in changing times. The sphere of clinical knowledge is extending exponentially with new areas of specialization developing as a response to the volume and depth of knowledge required to understand any given specialty. Application of the complexity of knowledge required for optimal practice and to advance knowledge in the area of specialization requires such focus on that specialization that the patient as a whole is often forgotten. This has been compounded even further in the hospital environment where there is a fiscal imperative to base all care on the treatment of a principal disease

[1] Corresponding Author: Heather Grain, School of Public Health, La Trobe University, Victoria 3086, Australia; Email: H.Grain@latrobe.edu.au

(through diagnosis related grouping funding systems) [1]. In this instance the focus can be so strongly restricted to the given condition that the other requirements of for the patients care can be forgotten. This problem is demonstrated by the example of Elsie.

### *1.2. Elsie's Story*

Elsie's local doctor was concerned at her increasing paranoia. The local doctor who knew the family extremely well discussed Elsie's problems with her daughter and sister and referred her for psychological assessment at the local hospital. While waiting in the emergency department she had a small stroke. From that point of time on her treatment was not just focused upon the stroke, an approach her family considered reasonable, but focused to the exclusion of all else. As a result there was no psychological assessment and no plan developed on how to encourage her to participate in the rehabilitation process. She was hostile to that process and though clinically was considered able to recover almost all of her mobility she did not and was discharged to a nursing home, where she still resides.

### *1.3. The Patient's World*

Just as clinical practice has changed, so has the environment of the patient. The education of the citizen and the open availability of knowledge through the internet, through literature and the media have not only awoken the individual's curiosity about health care but also their ability to obtain information about alternative diagnoses and treatment opinions.

In the past the patient had only the treating doctor, and possibly a second opinion of another health care professional upon whom to rely. In some cases this was extended to the knowledge in the community, the 'wise woman' or Sharman in whom local knowledge of herbs and traditional medicines rested. Today alternative sources of information are growing daily, access to traditional medicines, not only of our own cultures, but of other cultures of the world have been added to the knowledge of traditional western medicine. The patient who arrives in the doctor's office with a group of printouts from the internet about their symptoms and a desire to discuss the options and understand more about their clinical care present a great challenge to clinical practice and to the patterns of power in that relationship.[2, 3].

Patients and doctors are people who each like to feel that they have some control over their lives. Most people desire control of their bodies and health care and doctors have an equal desire to solve the patient's presenting problem in the manner their experience indicates would be most effective.

## 2. Doctor's Relationship Perspective

Though research indicates that doctors, particularly more recent graduates are keen to involve the patient in their care and meet patient needs [4, 5], this mutually desired consultation process is not well supported by funding models such as those used in Australian general practice which is based upon a fee for service model that makes the business of clinical practice dependant upon 'processing' as many people each day as possible.

These fiscal considerations have lead to increased large practices where there is less likelihood that the individual clinical will have any real understanding of the patient's social or family situation and less opportunity to find out about these issues. The words 'how's the family' were common when I was a child visiting my family doctor, who had treated my family, my cousins, aunts, uncles and grandparents. The son and daughter in law of that doctor continues to treat my mother… a circumstance that helped her remain in her own home and independent much longer than expected.

The education of medical staff includes a wide range of physiological, anatomical, pathological, pharmaceutical and other technical knowledge. The addition of significant communication skills to the education program would stretch an already stressed education process. A simple example of an educational gap is the poor ability of many medical professionals to explain the clinical process in lay terms without talking down to the patient.

The increasing patient desire for a partnership approach is difficult for doctors who are conscious of the issues of litigation. The need to provide clinical care of the highest quality is an imperative and if the patient wants an alternative approach this can be a significant inhibitor to allowing the patient the control they desire. The capacity of health record systems to record both the advice provided to the patient, and the explanation of potential repercussions of patient decisions, along with the patient's acknowledgement of these details offers the potential to more clearly define the patient's responsibility for choices made about care. These discussions could and should have occurred in the past, but appear to have been rare.

The government is becoming increasingly paternalistic also. There are rules about sharing health information, particularly information about 'sensitive' issues such as mental and sexual health. At first glance these may seem to be sound decisions, but there are patients who would prefer to share this information openly – as they believe that the care they will receive will be improved if their full history is known.

It is disturbing, and surprising to many health consumers that many doctors believe that they see the patient for all of their health care. In Australia this is certainly not the case. Consumer research indicates that most people see 2 – 3 general practitioners for their care [6], for example a doctor near their work, another might be seen for gynaecological problems, and the 'family doctor' for important or more serious issues. This lack of understanding can result in a lack of explanation to the patient of the importance of being able to explain their health status, history and treatments to all of their care providers.

## 3. Patient's Relationship Perspective

Patients expect a clinician who has appropriate clinical knowledge to assist them with their health issue. Increasingly patients' demands of their doctors are influenced by two divergent opinions.

Some patients feel that doctor's a busy people and acceptance of a less personal approach than in the past. Associated with this attitude or belief is a need for independence and self determination in healthcare, less reliance on the doctor and his skills, and in some cases a reduction in trust in the doctor.

There is also a patient opinion that doctors provide a service for which the patient is paying (directly or indirectly) and therefore the patient has a right to expect their questions to be answered in full. The "it's my time, I'm paying for it" attitude.

Patients often believe that doctors already have electronic health records and therefore that the doctor will know their family circumstances, and social situation from their previous encounters with the service provider or their organization [4]. For example when Jim visited his doctor he received the best advice according to clinical best practice, and was given a prescription for the most suitable medication to treat his condition, however a lack of understanding of Jim's social circumstance meant that the doctor did not consider the cost of the drug and didn't understand that Jim wouldn't be able to afford to have the prescription filled.

Patients are less inclined to repeat information they have told one provider in the system when they meet another provider – information transfer is assumed, but this doesn't always happen.

Patients want control of information access and sharing – where information is made available when required (which they assume is already happening) and that information will not be shared if the patient doesn't want it to be. Patients still require the ability to have a 'private' conversation with their health care professional.

## 4. Research in this Area

A review of the literature for doctor-patient relationship on PubMed and MedLine showed a wealth of research (more than 300,000 papers were returned). However a review of the first 100 papers retrieved from these searches (n=200) showed that 93% (n=186) of these articles represented either the doctor's or the patient's perspective, very few actually considered each of the investigated areas from both perspectives. This lack of investigation of the actual relationship, rather than the perception of the relationship from either 'side' is considered a serious limitation of the existing research. The most common topic covered in these 200 papers is the issue of access control and privacy. The issue of trust and mutual respect and understanding were not a major focus of the research material.

## 5. Summary of Issues

Though there is clearly a need for additional research in this area, in order to more clearly understand not only the issues, but the most effective approach to improve the relationship and the capacity to contribute to the relationship. The main issues are summarized below.

### *5.1. Issues for the Doctor/System*

Doctors have been responsible for patient care for so long that they are often concerned at the changes inherent in transfer of some of that responsibility to the patient.

- Skills to assist the patient in their decision making,
- Responsibility for care and skill not for decisions.
- Financial environment that acknowledges the extra time taken for
    - patient decision support and education and
    - explaining and understanding consent options and the need to share information

- Organizational departmentalization.
- Litigation – requirement to provide best practice can override patient desires. Legislative requirements can inhibit the ability for partnership and information access, even when desired by the patient.
- Communication
    - Social and family circumstance information access and use
    - Patient assumptions of information sharing
- Naivety of the doctor, there is a lack of understanding amongst some doctors that the way patients seek healthcare and the diversity of opinion they use is no longer as centered on the individual patient-doctor relationship.

### *5.2. Patient's Perspective*

Patients expect their care providers to be caring and to have the requisite knowledge of medicine, not to be responsible for the patient's life. They also expect that the care providers will listen to, and respect the patient's issues and preferences.

- Doctor's are busy, don't know me and sometimes don't care – I need to be responsible for my own care.
- I'm paying for the doctor's time – they should explain everything, and spend as much time as I need.
- I have control of
    - Access to information (restriction and openness)
- Doctors talk to each other – when a referral occurs the next treating doctor will have all the information they need from the referring doctor.
- The doctor will make sure that I understand
    - The disease process (what to expect)
    - The options, risk factors, lifestyle choices, alternative treatments available
    - The process (what's going to happen to them, what they need to do)

To those of us who work in health care it is clear that there are many assumptions and perceptions held by both the doctors and the patients that do not represent the way the system actually works. Though there is considerable research still required the simple rules that we should not assume that the relationships that exist are as simple or as one sided as seem to be the case.

It does seem clear that if the intended improvements in health outcomes desired by health care governance organizations around the world are to effect the changes desired improved capacity of doctors to engage in effective patient-doctor relationships need to be empowered, and the patients trust and capacity to engage with the doctor needs to be encouraged.

## References

[1] Victorian Government Department of Human Services, "WEIS8 2000-2001 Victorian Cost Weights" (2001).

[2] The Albany Consulting Group, Ian Cameron Research, ARTD Research and Management Consultants, "Integrating Consumer Views about Quality in General Practice" (Consumers' Health Forum and the Commonwealth Department of Human Services and Health, 1996.

[3] Grain H. In: Conrick M (Edr.) *Health Informatics: transforming Healthcare with Technology,* pp. 333-344. Thomson Social Science Press, Melbourne, 2006.
[4] La Puma J. *Managed Care Magazine* **January**, 1996.
[5] Schneider SH. *Journal of Evaluation in Clinical Practice*, (2008).
[6] National Electronic Decision Support Taskforce, "Electronic Decision Support for Australia's Health Sector". Department of Health and Aging, 2002.

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# Finland's Strategy and Implementation of Citizens' Access to Health Information

Pekka RUOTSALAINEN [a 1], Anna-Kaisa IIVARI [b], Persephone DOUPI [a]
[a] *National Research and Development Centre for Welfare and Health (STAKES), Unit for eHealth and eWelfare, Helsinki, Finland*
[b] *Finnish Ministry of Social Affairs and Health, Helsinki, Finland*

**Abstract.** The strategy for utilizing information technology in the field of social welfare and health care in Finland was published in 1996. It was redefined in the year 2006. This updated strategy defined basic principles how digitized EHRs should be stored, accessed, disclosed and archived. The strategy together with new legislation opened the right to patients and citizens to access their own EHRs, ePrescriptions and audit-logs via the Internet. A national WEB-service platform forms the base for both public and private eHealth applications. National identification and PKI-services cover health professionals, patients and entities. Citizen's consent management is provided at national level. The access to personal health information is managed using rules derived from legislation. The roll-out of the national health information infrastructure with citizen access to personal health information should by law be finalized before the end of 2011. The implementation of the NHII is demanding, but the real challenge is to clearly understand what the impacts of citizen access to personal health information are and to what direction this kind of services should be developed. At the present state, the Finnish EHR-archive contains only information created by a health professional. Citizens' eHealth services can not be limited to the use of regulated EHR data and ePrescriptions. For health promotion, proactive prevention and health prediction more comprehensive information is needed. Therefore the next step is to develop legislation and to build a trusted environment for the use and access of heterogeneous health and welfare information.

**Keywords.** Electronic health record, citizen access, EHR-systems, security services

## Introduction

The Ministry of Social Affairs and Health published its first 'Strategy for utilizing information technology in the field of social welfare and health care in Finland' in 1996 [1]. The underlying principle of the strategy was that ICT should enable the placement of the citizen in the centre of the care process and of the management of seamless service chains. The strategy also proposed the development of regional information systems, and highlighted the need of better interoperability between local

[1] Corresponding Author: Pekka Ruotsalainen, Doctor in EE, Senior Lecturer, Research Professor; STAKES Unit for eHealth and eWelfare, National Research and Development Centre for Welfare and Health (STAKES), Lintulahdenkuja 4, FI-00530 Helsinki, Finland; Email: pekka.ruotsalainen@stakes.fi; URL: www.stakes.fi

EHR-systems The next important step was the Government Resolution of 11 April 2002, which defined that all service provider organizations must implement an EHR-system by the end of 2007.

The Information Society Programme Ministerial Committee chaired by the Prime Minister outlined the basic principles of the national health care information system architecture in March 2006 [2]. The architecture includes a set of national interoperability and security services and defines the way EHRs should be stored and disclosed (e.g. long term archiving of EHRs, security services, citizen's eHealth services and technical and semantic interoperability services).

## 1. Strategic Focus Areas for the Development of eHealth

The Finnish eHealth Road Map summarizes the major national policy lines during the past ten years and proceeds to chart future challenges, as well as present Finland's strategic outlines with regard to the European eHealth Action Plan targets set by the European Commission [3].

Finland's strategic choices in the development of eHealth are:

- Creation of a trusted eHealth environment supported by legislation,
- Comprehensive digitization of customer data,
- Development of the semantic and technical interoperability of EHRs,
- Maintenance of online information to support decision-making,
- Strengthening of the participation of citizens and patients,
- Ensuring that citizens have access to high-quality health information,
- Enabling access for citizens to their own EHRs, health information and data disclosure logs,
- The development and implementation of the national health information infrastructure and an open platform for citizen access to health information, and
- The development of a national trusted platform for a wide variety of eHealth applications.

Derived from these strategic focus areas, the Ministry of Social Affairs and Health has initiated projects for the development of technical and semantic interoperability of regulated EHRs, building the national trusted service-oriented communication platform for health professionals and for enabling citizens to both access their personal records and control who else can access these records.

## 2. Regulatory Measures

The long term tradition in Finland has been to develop top-down national strategy and supporting legislation at the same time. During the years 2005-2007 new legislation has been developed.

An act on the processing and management of electronic health care and social welfare client information was created to both regulate and support the new national information infrastructure (NHII). Parallel to this regulation effort on act on electronic prescriptions was developed. The new legislation requires health care organizations to join to use NHII services within a transition period (2009-2011).

The recently created acts regulate the way EHRs and ePrescriptions are accessed, disclosed and archived. Regulations also define mandatory security services that every EHR-system and the national platform shall include.

The Act on the use and management of electronic client information in social welfare and health care (shortly named Client Data Act) [4], and the Act on ePrescribing [5] together with the Act on patient rights opened new rights for patients and citizens. These three acts offer the following rights:

- The patient has the right to opt-out the disclosure of his/her EHR,
- The disclosure of a patient's EHR should be based on informed consent and patient-doctor relationship,
- Overriding of the citizen's consent is possible only in exceptional situations specified in the legislation,
- The patient has the right to access using ICT-tools (e.g. the Internet) both his own EHRs and also the disclosure log,
- Service providers must inform patients of all services they are providing,
- The patient has the right to abstain of the use of ePrescription,
- In the case of accepting the ePrescription, patients should always receive an instruction (in paper or electronic form) including information on the content of the ePrescription,
- The ePrescription can be cancelled on behalf of the patient,
- Based on the patient's consent the physician and the pharmacist can access the patient's previous ePrescriptions stored in the national ePrescribing repository,
- The patient has the right to access audit logs containing information on who has accessed his prescriptions, when and for what purpose, and
- Using the Internet, the patient can access his ePrescriptions and utilization logs.

All the above mentioned rights apply not only to the public EHRs, but also to the records of private healthcare service providers.

## 3. The Management of Citizens' Access

Based on the Client Data Act, citizens or clients can access their personal health information stored in the national EHR-archive and ePrescription repository. Access can be realized using ICT-services (e.g. the Internet). Citizens or patients can also access the audit-logs managed by the national EHR-archive. Access management is based on rules derived from legislation and norms. The basic rules are:

- Citizens or patients must be identified either with the help of national PKI-services or by using second password services managed by the private bank sector,
- Citizens can access at any time the EHR-disclosure log of the national EHR-archive,
- Citizens can access their own ePrescriptions stored in the national prescription database,
- Citizens can access only archived documents named in the Client Data Act (e.g. laboratory results, care summaries and referrals),

- The responsible physician can temporary lock selected parts of the EHR, if for medical reasons it is necessary to meet personally with the patient before allowing electronic access.
- In situations where access can cause harm to the patients' care process, it is possible to restrict or limit electronic access.

Because clients can manage dynamically their own personal consent profiles, they can also dynamically manage the consent-based access process.

The Ministry of Social Affairs and Health has defined a stepwise process for the implementation of citizens' access to their own EHRs. In the first phase citizens will be able to access their care summaries, laboratory results and referrals stored in the national EHR-archive. During this phase, the responsible physician will have the right to prevent access in the case the information can cause serious harm to the patient. Depending on the experiences gathered from this first step, it may be possible to expand the citizens' access rights to cover the whole of the EHR without any restrictions.

## 4. National eHealth Communication Architecture and Citizen Access

The basic building blocks of the Finnish eHealth architecture are: a WEB-service platform, security services, the digital archive for EHRs, the ePrescription repository, consent management services and terminology services (Figure 1). On top of the Web-services there is also a portal for citizen access to EHRs, audit-logs and ePrescriptions [6].

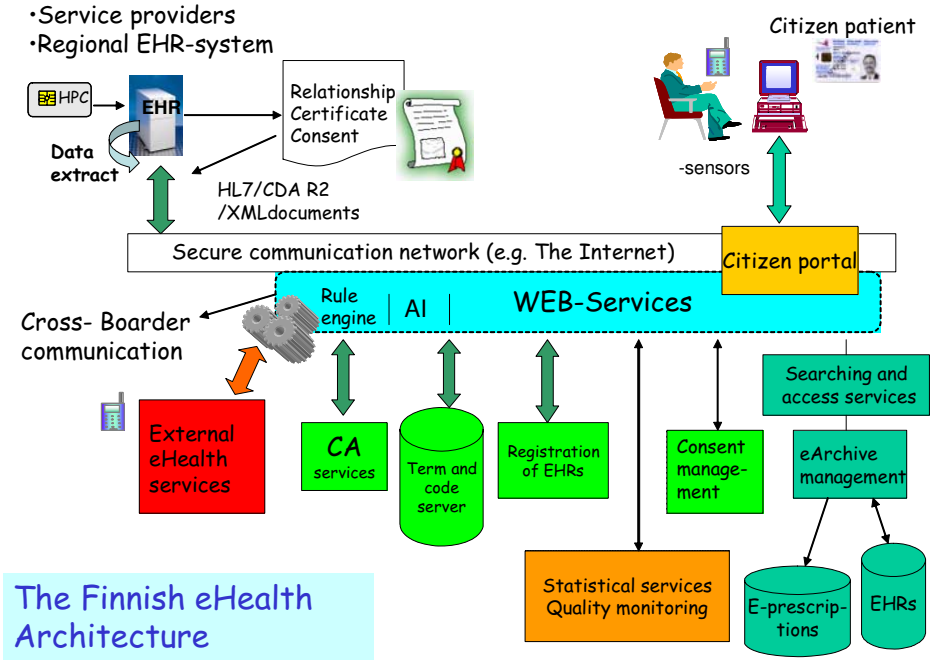


**Figure 1.** Building blocks of the Finnish eHealth architecture

Common security services include identification and authentication of patients, citizens, health professionals and communication entities.

Information collected from local EHR-systems and sent to the eArchive includes all essential patient data. EHRs are transferred to the eArchive and also preserved in the form of HL7 CDA documents. In the long term the eArchive creates a virtual lifelong EHR for every citizen.

The core of consent mangement is a centralised consent and opt-out repository. All clients will have a peronal consent profile and they can create, modify and delete their own consents during any care event or at any other time via the citizen portal.

The common national services form a unique platform for both public and private eHealth services. The platform is also an enabler for different kind of citizens' eHealth services. The SOA-architecture and WEB-service make it easy for SMEs both to develop and connect their own services to the NHII. To make the platform and its services trusted, the Ministry of Social Affairs and Health is defining certification criteria which every eHealth service shall meet before it can be part of the NHII services.

There are two basic methods to connect external citizen services to the NHII. The primary way is to build services on the top of the citizen portal. A second possibility is to link an external application directly to the WEB-service layer of the platform. The latter option enables the development of eHealth services which are not managed by regulated health service providers.

## 5. Access to eHealth and Information Services

Both public and private administrators and service provider organizations are developing eHealth services for citizens on top of the NHII. The spectrum of those services is quite wide, starting from health promotion and self care services, to cost and quality of care management.

Typical public eHealth services which can be accessed via the citizen portal are health promotion services. The National Public Health Institute is building a health information portal for citizens (tervesuomi.fi). This portal is the official channel to reliable health information for Finnish people. The portal is developed utilizing Semantic Web technologies. In the future other services will be developed as services for the management of personal vaccination history.

Services created by public health administrators (e.g. municipalities, health centers and secondary care hospital regions) are:

- Municipal and regional self-care disease management applications for major chronic diseases (e.g. diabetes, asthma and high blood pressure),
- e-mail consultations,
- Booking services focused on the management of seamless care chains,
- Regional call centre services (e.g. anonymous advise services, booking services and consultation services), and
- Mobile disease monitoring and advice services based on SMS-messaging.

Services developed by the private sector include:

- Patient ID-services (e.g. secondary password based identification services created by the bank sector),

- Access services to the ePrescription data base. Citizens can access the ePrescription repository via kiosks managed by private pharmacies,
- Information services of available health experts and their qualifications,
- Booking services, and
- Email consultation services.

The national architecture for eHealth services to citizens is in the planning phase at the moment. Some applications as booking, eConsultation and personal health records will be tested and evaluated first at the regional level. In the future the essential part of the citizens' eHealth platform will probably be created at national level.

## 6. Future Services based on Application Intelligence

The main role of the Finnish NHII is to be a trusted channel for accessing regulated EHRs and ePrescriptions. The common WEB-service platform enables also the development of next generation intelligent citizen-centered eHealth services (Figure 2).

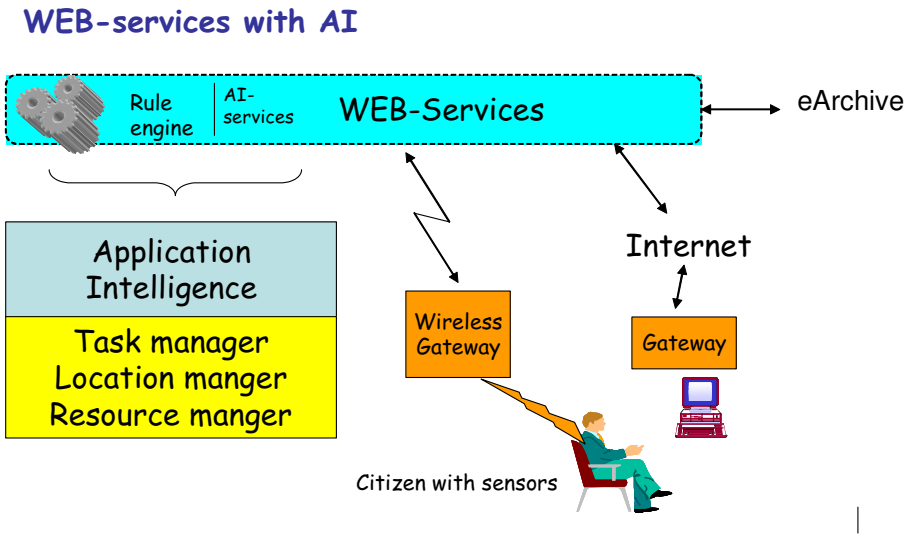


**Figure 2.** Intelligent eHealth services linked to the Finnish NHII

Information created by citizens themselves or captured from personal or home sensors can be collected and analyzed at the level of web-services using application intelligence software (figure 2). If the citizen or client allows it, those AI-applications can combine personal health-related information, information of personal medication history and regulated EHR-information and make intelligent decisions based on the aggregated information.

The national platform will also act as the gateway and controlled access point to future European eHealth services.

## 7. Discussion

The Finnish national health information architecture offers a trusted information access and sharing platform both for clients and health professionals. It is flexible, based on standards and it is also service oriented. This platform simplifies the development of new eHealth applications and services. The Finnish solution offers to citizens new possibilities both to access their personal EHR-information and to control who is using their information.

At the present state, the EHR-archive contains only information created by a health professional. The collection and use of health information created by clients themselves is neither part of the NHII nor regulated at present. On the other hand, citizens' eHealth services can not be limited to the use of regulated EHR data and ePrescriptions. For health promotion, proactive prevention and health prediction more comprehensive information is needed. Therefore it is necessary to develop the present legislation in such a way that it will build a trusted environment for the use and access of heterogeneous health and welfare information.

Currently we do not yet understand clearly enough the potential impacts of citizen access to personal health information, and the possible directions this sort of services could be developed. Because the Finnish architecture uses rule-based access control, it is easy to modify the rules in the future, if and as necessary.

There are two essential prerequisites for the successful roll-out of citizen-centered eHealth services: trusted access and use of heterogeneous health information, and well defined responsibilities. The former requires the development of new information models enabling trusted access to heterogeneous, multi-source personal health information, and the latter requires new levels of regulation.

## References

[1] A Strategy for Utilisation of Information and Communication Technology in Welfare and Health (in Finnish). Working Group report the Ministry of Social Affairs and Health 1996), 1995:27, Helsinki 1996.

[2] Iivari A. and Ruotsalainen P (editors). Principles for the national information system architecture for healthcare (in Finnish). The Ministry of Social Affairs and Health, reports 2006:8.

[3] Iivari A. Ruotsalainen P., eHealth Road Map - Finland, The Ministry of Social Affairs and Health, reports 2007:15.

[4] Act on the use and management of electronic client information in social welfare and health care, act 159/2007.

[5] Act on electronic prescribing, act 61/2007.

[6] Ruotsalainen P., The Finnish eHealth Architecture - a Tool for Nationwide EHR-sharing and Service Quality monitoring, CASCOM WS, October 7th Leipzig, Germany

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# How Can the German Electronic Health Card Support Patient's Role in Care Management

Peter PHAROW [a 1], Bernd BLOBEL [a] and Claudia HILDEBRAND [b]
[a] *eHealth Competence Center, University of Regensburg Medical Center, Germany*
[b] *Institute for Biological and Medical Imaging / Medis, Helmholtz Zentrum München, German Research Center for Environmental Health, Neuherberg, Germany*

**Abstract.** All types of advanced communication, collaboration, and cooperation in healthcare require a strong involvement of all addressed parties including health professionals and patients. Modern healthcare aims at involving patients having them take over responsibility for their own health status. Allowing them to take on their changed roles as emancipated partners in advanced care management, health professionals need to be educated and patients need to be empowered. From a security viewpoint, health issues have to be communicated via trusted health networks. To provide communication and cooperation between professionals and patients as well as to guarantee the required level of involvement of patients in shared care management environments, cards are widely used as person identifiers, on the one hand, and as security tokens, on the other. Being introduced as storage media and portable personalized application system, cards enable a patient controlled access to personalized health services as well as proper use and exchange of personal health data for specific purposes such as emergency. Furthermore, cards allow access to the wider electronic patient record via pointers or tickets. Cards can empower patients. The German Electronic Health Card (eGK) shall thus support care management and specific workflow processes e.g. for prescription and disease management. Regardless whether designed as data or pointer card - international standardization is a prerequisite also for national solutions. The more information patients have regarding different procedures and processes in healthcare, the more are they able to play their dedicated role within care management. Cards can and will contribute by allowing patients to get controlled access to administrative and medical data stored either on cards or in networks. Card holders determine who has access to their health information.

**Keywords.** Patient Empowerment, Patient Involvement, Patient Data Cards, Health Cards, Personalized Portable Devices, Security Infrastructure, Electronic Health Record, Security Policy

## Introduction

Knowledge accumulated in recent decades showed that both the information flows within a domain and the transfer of information between domains are the very basis of any kind of human progress. Professional knowledge becomes more valuable when shared with other professionals. This is especially true for healthcare. Distributed

[1] Corresponding Author: Peter Pharow, eHealth Competence Center, University of Regensburg Medical Center, Germany. Franz-Josef-Strauss-Allee 11, D-93053 Regensburg. URL: http://www.ehealth-cc.de

collaborative and coordinated care of patients in the sense of shared care increases the quality and efficiency of health [1]. This is what most health systems in the developed countries throughout the world currently aim for. Additionally, healthcare administration and care management focus more and more on preventive care. The citizen himself / herself is responsible for this dedicated part of health. This indeed requires more information flows, but it changes the role of the patient as well.

Regardless whether integration of information is considered for domains like informatics, bio-informatics, biomedical engineering, applied and clinical informatics, or for information systems and informatics education - it is always the collaboration and exchange of knowledge that matters [2]. Empowering the patients to take on their changing role in healthcare workflows and care management, and involving them in these healthcare processes are important pre-requisites for achieving effective and affordable healthcare many developed countries -among them Germany- aim for.

Health cards play an important role. They allow developing an integrated eHealth environment by integrating medical informatics, health informatics, patient integrity, and patient integration. Besides secure health cards and security tokens and their respective technical aspects, the role of cards in the process of patient integration, the problems concerning legal, social, societal, and ethical access rights, and related non-technical data protection and privacy aspects need to be considered [3]. As these aspects are definitely not limited to certain regions or nations, both developers and implementers have to look for European and even worldwide standardized or at least standards-based approaches.

## 1. Current Healthcare Challenges

While in past decades the main impact in medicine had been on acute medicine and the doctor had been considered as the "sole expert" for any individual's health, in recent years there has been a growing demand for co-operative approaches and citizen engagement. Thus healthcare has been moving from a physician / disease-centered approach to a patient-centered one. Modern healthcare aims at involving the citizen and at having him / her take over more responsibility for his / her own health status. New health-related technologies enable the patient to actively participate. Patient data cards and the internet as a ubiquitous communication platform both stipulate this approach. The wide-spread use of such cards along with the general access to information and communication media for both professional and citizen / patient offer a good chance for achieving high quality shared care. Each individual ought to be interested in staying healthy. Health -by its very nature- is something very personal. In typical Western communities, however, it is still the public health system which is mostly held responsible for healthcare.

### *1.1. Administrative and Organizational Challenges*

Rising healthcare costs and a growing elderly population make the public bodies ask for more contributions of the citizen. The involvement of the citizen but also the rights of the patients concerning his / her own health status was recognized a long time ago. In 1994, the United Nations Organization (UNO) passed a resolution on "Standard rules on equal chances for the disabled". This was the first ever legal framework for patients' rights [4]. In the same year, the Regional Office Europe of the World Health

Organization (WHO) set up the "Principles on the rights of patients in Europe", which stated that "Patients have the right to be fully informed on their health status…" [5].

A lot of countries adapted this and made it part of their own constitution. In October 2004, the World Health Organization (WHO) officially launched the "World Alliance for Patient Safety" dedicated to "bringing significant benefits to patients in countries rich and poor, developed and developing, in all corners of the globe" [6]. Since January 1st, 2003 all U.K. National Health System (NHS) bodies have had a legal duty to involve and consult the public. The new German Social and Health Insurance Modernization Law (GKV-Modernisierungsgesetz, GMG) of January 2004 requires a patient ombudsperson on national level [7]. Several healthcare organizations, e.g. "The Irish Society for Quality and Safety in Healthcare", are issuing guidelines to citizens on how to become actively involved [8]. Respect for the treating healthcare personnel and achieving a good partnership are important issues.

People are ready to take on more responsibility in the care process and are interested to benefit from modern technologies, such as the internet for eHealth information and health cards for communication. On top of that, many citizens are willing to invest in their health, as it can be seen by the growing public and personal expenditure on health products and services.

In order to actively cooperate, the citizen requires information. Several patient empowerment projects, activities, and initiatives proved that citizens want to be better informed on their own health status [9], [10], [11], [12]. Modern communication, the internet and the introduction of Electronic Health Records (EHR) as well as secure token technologies including smart cards help to create educated and well-informed citizens. On top of that, rising healthcare costs and a growing elderly population - make the public bodies ask for contributions of the citizen.

Patients / citizens can be involved at different levels of contact ranging from the very treatment to strategic policy making. The patient who gets involved wants to be treated as an equal partner with specific contributions. Collaborative partnerships between citizen and healthcare provider need to be supported.

While several national and regional projects, surveys and activities are claiming that citizens are seeking a greater role; others claim that the majority of people is simply not interested in getting involved. And there are, of course, those who are only think of healthcare when they are in need of it.

### *1.2. Patient Empowerment and Patient Involvement*

Engaged citizens will profit from advanced healthcare systems as they have better outcomes. New health policies, increasing patient needs and decreasing health budgets necessitate patient empowerment in all care management processes and procedures.

Patient empowerment means that citizens have to take on their share of responsibility. Citizens have to realize that health is a concern of theirs even while they are not in need of any care. This implies citizens do understand the system. Only if those are aware of what is happening, when and why, will they understand the healthcare process and will they be able to influence it. This will allow them to build up the necessary confidence in the new system -which itself is a major requirement if one expects patients to accept any change of behavior that might be required.

Healthcare providers and politicians have to realize that healthcare systems and services can only be improved if citizens are actively supporting the system. Consistent patient involvement, however, will bring about many changes. Patients will be

involved in decision making, e.g. in co-defining the treatment plan, and they may even influence their medication. Patients will be able to choose their care provider based on comparative criteria. They might even be able to direct their care plan as this might add to the patients' safety which is the uppermost aim of healthcare processes [13], while expectations of the health professionals as well as those of the patient towards the doctor-patient relationship may vitally influence the outcome of an examination [9].

The patient has to be informed; he / she has to be able to decide and has to be able to communicate. This poses many challenges, as it means that besides the care provider who needs to be trained on collaborative partnership, the necessary tools and education will have to be provided. On the political level respective decisions will have to be taken [14]. Not only will everyone be entitled to access the information in an easy and convenient manner, but he / she also needs to be educated in the proper use of available tools. A recent study on internet use in Germany revealed that while the larger part of the population is using the internet to access health related information, more sophisticated applications are left to the internet specialists [12].

Special groups, such as less educated or disabled persons need to be included. Aspects like accessibility to and usability of information by implementing barrier-free user interfaces become more and more important.

Special requests of ethnical groups will have to be taken seriously. Though these special groups of citizens may only be small, a large proportion of the potential market will be lost if ignored. Each and every single user shall be entitled to access information, regardless whether it's with or without the use of external supporting devices. This is also true for users who can't see (e.g. blind people) or users who are physically impaired and can't use ordinary input devices like keyboard, mouse and joystick. Users have to be able to technically read the content of respective information sources as well as to understand its meaning.

### *1.3. Legal and Ethical Challenges*

Several laws and regulations in Europe state that health and medical care should be based on respect for the patient's self determination and integrity. The aim of self-determination in this respect and according to the legislative preparatory work has always been to ensure that individuals seeking help from the healthcare system retain their dignity and integrity. The processes of care and treatment are to be planned and implemented in close consultation with the patient. This is a basic ethical principle [11].

The technical concepts of data integrity are still being used vaguely and ambiguously. They need to be explained to citizens in order to facilitate a comprehensive discussion on how to realize privacy. Several surveys and studies aimed at finding an effective definition of integrity and privacy, and to suggest criteria that delineate the characteristics of a good health professional, who is willing and able to respect the patient's privacy. Data protection, data integrity and data security have to be backed by respective legal regulations. Patient group representatives are increasingly considered valuable partners even by health policy decision makers [6], [14], [15].

A dedicated patient health card (PHC) can act as a means to technically and ethically strengthen the role of the citizen. The ethical dimension as such plays an important role in any health business as patient involvement and patient empowerment always needs to lead to enhanced patient satisfaction. Thus, a PHC has multiple related functionalities [16]. It can be used for purely administrative reasons, but also support the communication between care providers. It can also improve data security. In either

case the patient has to support this process -at minimum- by presenting the card when necessary. Thus the patient is actively involved. The DIABCARD pilot showed that over 90 percent of the participating persons with diabetes felt even better cared for and empowered by carrying the DIABCARD patient health card [17].

Any kind of involvement requires a certain level of process understanding (in terms of user awareness, user confidence, and user acceptance). Can a health card support this? Can it at least support the provision of this? We think it can, it should, and it shall.

### *1.4. Secure Patient Health Token and its Increasing Role*

Many technological solutions have been developed and implemented for handling person-related administrative or medical information in healthcare in the last 30 years [18]. These technologies can be distinguished by the deployed medium and its purpose, and by the mechanisms and functions provided [19].

Memory cards have been introduced widely (e.g. the current European Health Insurance Card). They are originally based on the idea of simple paper or plastic cards that can only be written to once and read many times. New generation cards are being used as access cards, as storage cards, as identity cards, as authentication cards, as signature cards, as encoding / decoding cards, etc. Sometimes, cards are also classified by their -in this context medical- dedication for supporting specific ailments (e.g. the DIABCARD for supporting persons with diabetes) [17].

Considering both, structure and mechanisms, programmable processing facilities have been established. These processor cards are sometimes equipped with specific co-processors to support special complex algorithms and are also known as smart cards. The application of a card is often linked to a specific mechanism which provides the functions required. Frequently, several functions are realized deploying the same physical card (multi-functional card).

Apart from cards that are only used to access rooms, applications, systems, or information sources respectively, smart cards in healthcare can be deployed in several different ways. On the one hand, the card can bear the vital information subset of a health record. In case of a Patient Data Cards (PDC) designed and used mainly as a storage card, e.g., relevant medical data can be stored there as parts (sub-sets, extracts) of an Electronic Health Record [20], [21]. On the other hand, the card may solely be used as a pointer providing references and links to information stored in shared-care networked systems. The latter approach seems to be the more promising one as medical data are dynamic data, and current cards can only bear parts of the information that is needed for a comprehensive EHR structure (see below).

As authentication (identification and verification) is the very basis for each single security service, electronic health information systems -like any other system- need to have a security infrastructure supporting the appropriate carrier (card, token) for an authorized access to virtually any information (see chapter 5). Smart cards are now being increasingly used as Patient Data Cards and as Health Professional Cards (HPC). Respective standardization activities started back in 1997 [22], [23] proceeding until today [24], [25] to further strengthen the co-operation between the patient and the health professionals in the healthcare processes.

The specifications for electronic health cards differ in the various countries as far as the structure of storing data on card is concerned. Some specifications intend to store as much data as possible whereas others seem to aim for the combination of card and

network. As the storage capacity of cards is limited, and as the Electronic Health Record is considered the core application of future-proof health information systems, future card generations will most likely act as access tools or tokens rather than as carriers of real medical information. When secure online access to information can be guaranteed wherever needed the health card as an offline data storage device will no longer be required as sole medical record carrier. It might, however, occupy niches.

### *1.5. eHealth Security Infrastructure and its Services*

In Europe and other parts of the globe, smart cards are frequently used for enabling trustworthy communication and application security services [19]. The basic principle reflects a certified binding of a principal (according to OMG's definition actors in the health systems including its informational support such as persons, organizations, systems, devices, applications, components, even single objects, etc.) to its electronic unique identifier or assigned properties, rights and duties, also called attributes of that principal. Communication security services concern the identification and authentication of communicating principals. In an end-to-end secure communication environment (object security), these services are used for authentication and control of access rights of principals communicating as well as integrity, confidentiality, and accountability including non-repudiation of information exchanged. For object security, security-aware principals are needed.

On the other hand, integrity and confidentiality of communicated data may also be provided at system level transparent to the application and the user following -but not requiring- the user's awareness for those security measures (channel security). Application security services deal with authorization and access control to data and functions. Besides, they also cover accountability of principals, audit track and auditing of these principals and services ensuring integrity, confidentiality of data and functions. In both concepts, notary's services have been established. Another important requirement for both communication and application security concerns the availability of information and services. More information regarding the different safety and security categories, services, and underlying mechanisms as well as algorithms and data structures can be found, e.g., in [26], [27].

## 2. Standardized eHealth Solutions based on Cards

When providing open, interoperable and scalable solutions for empowering and involving citizens and patients worldwide and including their respective cross-border activities, these solutions must strictly be based on international standards. Otherwise a French health professional will not be able to read the data of his / her German patient and vice versa. This aims at standardizing not only the pure technology of cards and their respective readers, application access interfaces, application programming interfaces, and the underlying card infrastructure framework but all aspects and components of modern information systems including data structures, functional and semantic interoperability, security, safety, privacy, etc. This also includes aspects of policies, ethical aspects, protection of persons by protecting their data, and many other information-related aspects.

### 2.1. International Standardization Requirements

As standardization is a very complex domain, a few statements about card-related standards shall be taken as examples to describe how standardized solutions can positively influence not only aspects of safety, security and availability but also increase the level of patient involvement and patient empowerment. Eventually, standardized person-related cards will enable the use of established security infrastructure services (see, e.g., the previous chapter).

Regarding the requirements for interoperable Patient Data Cards, series of standards have been specified at international level by ISO TC 215 "Health Informatics". After having identified both needs and requirements for such cards, the standardization experts have defined a framework for card-related specification of medical and administrative content. ISO TC 215 does not intend to standardize card-related technology itself but only the health-related structures on such types of cards. Security is an important part of any such solution. ISO TC 215 has therefore been defined by both security experts as well as by card experts.

Person-related data carried on a data card can be categorized into three types: identification data (of the device itself and of the individual the data it carries relates to), administrative data related to the card owner, and the respective medical (clinical) data. It is important to realize that a given healthcare data card "de facto" has to contain device data and identification data and can -in addition- contain administrative and clinical data. Furthermore, patient data cards may support the collaboration with network-based systems. For that purpose, any type of link information was specified. One of the main application areas for patient data cards is the electronic prescription.

### 2.2. ISO 21549 Health Informatics - Patient Data Cards

A data card essentially provides specific answers to definite queries whilst at the same time a need to optimize the use of memory by avoiding redundancies remains. Using a UML Class Diagram, the following figure shows the overall structure for patient health card data according to the parts described in ISO 21549 [23].

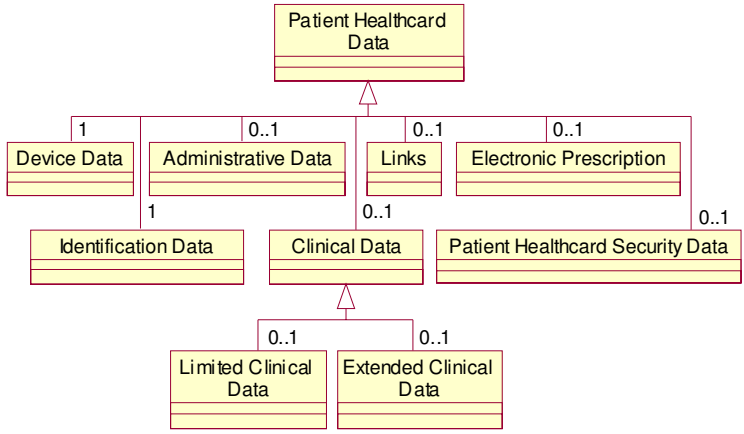


**Figure 1.** ISO 21549 Data Structure and Relations

### *2.2.1. The Existing Parts of ISO 21549*

The first part of ISO 21549 gives an overview on what is tackled by such a series of standards (see figure 1). Part 1 introduces the multi-part standard that defines data structures held on patient health cards compliant with the physical dimensions of ID-1 cards as defined by ISO/IEC 7816. This part does not apply to multi-application cards. It defines a general structure for the different types of data, which are defined in the other parts of the standard, using UML notation. Several countries did require this in their national health card implementation specifications.

Part 2 is dedicated to data items and structures that are part of every single health card. It establishes a common framework for the content and the structure of common objects used to construct other data-object data held on patient healthcare data cards, or references thereof. It specifies the basic structure of the data but does not specify or mandate particular data-sets for storage on devices. The latter is done in the other parts.

Part 3 defines and describes the limited clinical data objects used in, or referenced by, patient-held health data cards using UML, plain text and abstract syntax notation (ASN.1). It specifies the basic structure of the data contained within the data object "Limited Clinical Data" but does not specify or mandate particular data-sets for storage on devices. In particular, the data contained within the data objects in "Limited Clinical Data" are intended to aid the delivery of emergency care, but are by themselves neither intended, nor suitable, for the provision of a comprehensive set of medical information.

In the meantime, parts 1 to 3 run through the process of evaluation after three years. This is a mandatory process allowing the standardization experts to either keep the standard as it is, reject is for several reasons, or undertake the difficult task of adopting comments that arrived during these first three years.

Part 4 specifies the basic structure of the data contained within the data object "Extended Clinical Data", but does not specify or mandate particular data-sets for storage on devices. In order to facilitate interoperability, whenever an application is built for use in the healthcare domain in compliance with this standard, data items required for that application shall be drawn from a defined list of objects. These shall then be used in conjunction with other data defined in other parts of this standard.

Part 5 establishes a common framework for the content and the structure of "Identification Data" of the device-holder held on healthcare data cards. It specifies the basic structure of the data, but does not specify particular data-sets for storage on devices. The described data structures can accommodate suitable data objects specified elsewhere

- security functions and related services which are likely to be specified by users for data cards depending on their specific application, for example confidentiality protection, data integrity protection, and authentication of persons and devices related to these functions;
- initialization and issuing processes (which begin the operating lifetime of an individual data card, and by which the data card is prepared for the data to be subsequently communicated to it according to this standard), and
- access control services which may depend on active use of some data card classes such as microprocessor cards.

Part 6 specifies the basic structure of data contained within the data object "Administrative Data". It does not specify or mandate particular data-sets for storage on devices. In order to facilitate interoperability, whenever an application is built for use in the healthcare domain data items required for that application shall be drawn

from an existing list of objects (some of which are extensible). These shall then be used in conjunction with other data defined in other parts of ISO 21549. For delimiting the administrative data set of this standard from the identification data set of ISO 21549-5, the administrative data set shall contain health insurance data only.

Part 7 will define the structure for electronic prescription. This is on top of the priority list of most European countries as this use case seems to be the most promising one for economic and user acceptance reasons. In close collaboration with the newly established ISO TC 215 WG 6 "Medication Data", a data structure for a card-based electronic prescription process is being specified.

Parts 4 to 7 became standards during the course of the last two years. They are now in the process of being implemented in the different countries in real world scenarios. All comments, additions, changes, and other remarks are collected for an evaluation of these parts later on. For details on current status of work see [23].

### *2.2.2. Part 8 Links (the Working Draft)*

Part 8 is of specific importance for the future use of electronic health record structures and systems as this part intends to bridge card and network in a way that shall –and will- enhance patient involvement. As cards aren't able to bear complete information structures (including plain text, structured information, images, other multi-media information, etc.) regarding a patient's health status, networks will easily communicate this information in real time. Cards will therefore act as secure and reliable keys to this information in terms of an access token. To allow fulfilling this very important function, respective links, tickets, and pointers need to be stored on the card (URL, URN, online tickets, etc.). Part 8 of ISO 21549 will therefore define and standardize this type of structure [25].

### *2.2.3. Current Status of Ongoing ISO 21549 Work*

Almost all parts of ISO 21549 are already available to domain experts. Parts 1 to 3 became official ISO standards in May 2004. Several countries have already made the standard part of their national health card implementation strategies. ISO TC 215 launched ISO 21549 parts 4 to 7 recently.

Part 8 is still missing for several reasons. On the one hand, links and pointers as well as ticket structures need to be based on existing health record systems. Very few countries and regions do have EHR systems already in place. National health policies usually prioritize electronic prescriptions, immunization records, emergency data sets, etc., instead of a comprehensive Electronic Health Record. Other initiatives focus on EHR subsets or extracts.

Standardization is a very demanding process. Very few experts define many standards. Therefore, standardization takes a lot of time. Only recently have politics realized the importance of standardization. This means that a lot of the standardization work is being done by very dedicated persons on a voluntary basis as standardization work is still not being financed in Europe.

Additionally, are most of the parties in the healthcare domain not aware of existing and emerging standards as they are not actively involved in this process and because the Standards Developing Organizations (SDO) allow access to standards only on a commercial basis. So either the responsible parties need to take the financial risk to send their experts to the SDO without knowing whether or not the resulting standard

will fit their intentions. Alternatively, the parties need to buy standards without knowing whether or not they are applicable for their intentions.

Among other projects and initiatives, the project "BioHealth" [28] intends to collect, analyze, summarize, and wide-spread information on existing and emerging security standards in healthcare. Workshops and open meeting along with a respective documentation shall help keeping the interested community informed about the ongoing standardization work not only in ISO TC 215 but also in other SDO areas that are of importance for implementing standardized eHealth solutions world-wide [29].

### *2.3. National German eHealth Requirements*

The planned introduction of an Electronic Health Card (eGK) is considered to be a milestone in the dissemination of access to extended Electronic Health Records in Germany. Many additional issues are likely to result from the use of the Electronic Health Card. The role of the patient in the health care management process and the patient's enhanced access to his / her personal medical record are expected to change. A high level of acceptance of the electronic health card and extended electronic documentation procedures can furthermore be expected if ruling bodies manage to properly address all ethical, legal, and technological concerns of the public, and that appropriate incentives can successfully be established. Eventually, the health card can serve as a useful aid to support the ongoing implementation of disease management programs (DMP), integrated care centers (IV), and collaborative care centers (MVZ) for the most important chronic conditions in Germany [30].

#### *2.3.1. Patient Empowerment Strategies in Germany*

Patient empowerment as such is considered to be a very dynamic process in Germany and in all other countries alike. It affects the utilization of services, the aspect patient involvement, patient empowerment and patient satisfaction, and it addresses the aspects of health outcomes. Having a valid and reliable measure for the degree of having patients satisfied is indeed an important factor in understanding the effects of patient empowerment.

The principle aim of any activity (here the development and the nation-wide roll-out of the German Electronic Health Card) for involving patients into the processes of care management, and for empowering patients to play their dedicated role in the medical and welfare workflow is to identify a conceptual model of patient empowerment and to develop a scale that can be used to measure patient empowerment and satisfaction in the general community. This included identifying important factors involved in patient empowerment.

According to a study [31] made in Germany and in other countries recently, patient empowerment can be measured over six different domains: knowledge, access, advocacy, decision making, health status / outcomes, and literacy. Preliminary results of that study indicated that there exist varying degrees of empowerment in the population and that empowerment varies with age, socioeconomic status and education [31].

#### *2.3.2. The German Electronic Health Card Specification*

As said before, ethical and social aspects play an important role while announcing and developing technical solutions for advanced care management processes in Germany

and beyond. Safety, security and privacy are additional categories to properly be addressed in this context. So the technical specification details always need to be linked to social, administrative, organizational, societal, and other aspects as well. Access to patient-related data is thus clearly ruled in the respective legislation in Germany.

Respective German legislation rules that access to health card data is only allowed using the counterpart of the patient card, the health professional card (HPC in international context, HBA in German). The specification addresses advanced symmetric and asymmetric cryptography for the trustworthy functions of the card. Needless to say that the German health card specification addresses a smart card with sufficient level of security functions. The card supports both a card-to-card authentication and card-verifiable certificates [6], [9], [32].

From the viewpoint of technical security, the card contains -in a well-protected area of the card- asymmetric keys for authentication, for addressing encryption, and for electronic signatures. Furthermore, the card contains a symmetric key for card-to-card authentication, the required card-verifiable certificate(s) and optionally also X.509 certificates for accessing PKI functions.

### *2.3.3. The Services Addressed by the German Electronic Health Card*

The German Electronic Health Card -in order to fulfill the requirements of advanced health care management- contains a set of different functions. Some of them are mandatory ones whereas other are optional. The mandatory functions have to actively be supported by both patients and health professionals. Optional functions allow getting access to additional health services. Patients are free to choose whereas health professionals must offer the complete set of services to their patients.

The mandatory functions of the card according to the respective German legislation address the in principle well-known functionality of the former German Health Insurance Card (KVK) and contain the data of the insured person, the card holder. An extra mandatory feature of the new card is the electronic prescription. Up to five prescriptions (or tickets for prescriptions, according to the specification) can be stored on a single card. One prescription thereby contains one single medication in order to allow hiding specific "crucial" drugs while collecting "ordinary" ones just from the pharmacy next door.

The optional functions cover a much wider spectrum of services. It starts with the medication documentation covering all prescribed (and hopefully also all free access) medication details in order to find possible contra-indications. An emergency data set following in principle the respective ISO 21549 definition belongs to the options patients have while using their card. An important feature is of course the set of tickets and pointer to the patient's EHR and other sources of medical and care information. Billing details can be activated, and so can a patient safe allowing the patient to securely store personal information and statements bon emotions, use state, etc..

Enabling the described optional applications by well-informed patients is a pre-requisite for achieving the medical and financial advantages politicians, health care providers, and patient representatives are looking for while rolling out the German Electronic Health Card.

### *2.3.4. Patients in Care Management Processes*

Patients play an important role in care management. It's the patient who shall be in the center of al care processes. Being in the center of all workflow processes requires a

certain level of knowledge, information, and trust. The patient shall be satisfied with the treatment. This requires a patient empowerment based on patient involvement. The empowerment can be measured over six different domains. Among those are the level of knowledge, the access features, the advocacy, the way of decision making, the health status and the expected outcomes respectively, and the literacy. Additionally, there exist varying degrees of empowerment in the population and empowerment varies with dependencies related to age, socioeconomic status, and education. So, educational and training measures need to seriously address the six domains and the three dependencies as well.

The main aim of all health care and welfare management processes is a satisfied and health patient / citizen. The German Electronic Health Card allows the patient to actively control the distribution of personal medical / clinical information according to his / her personal interests and needs. Based on the card functions described earlier, the patient is able to specifically allow health professionals (family doctor, specialist, hospital, tertiary care, etc.) a dedicated access to that information. It's the patient who is in the center of the processes, and a security token like the health card and its security underlying functionality provides the patient with a sufficient set of functions to play his role in the workflow procedures.

## 3. Discussion

Recent demographic, economic, and social / societal conditions confront most of the developed countries with an immediate paradigm change for delivering high quality and efficient health services. In that context, healthcare systems have to consider individualized patient's care, also called personal care or personal health (pHealth), respectively. Interoperability requirements for ubiquitous personalized health services reach far beyond current concepts of health information integration among involved professional stakeholders and related Electronic Patient Records (EPR) and Electronic Health Records (EHR).

Future personal health platforms particularly have to maintain semantic interoperability among systems using different modalities and technologies, different knowledge representation and domain experts' languages as well as different coding schemes and terminologies to include home, personal and mobile systems. This paper aimed at introducing the evolving paradigm related to personal health information systems. Card will evolve towards devices, chips evolve towards embedded chips allowing a "medical" device to become a personalized, portable devices.

All industrial countries are faced with the challenge to ensure efficiency and quality of healthcare, independent of constraints in time, location and resources of principals involved. The challenge must be met despite of demographic developments towards aging population, increasing expectations on quality of life and lifestyle, growing demands for health services, rising costs for diagnostic and therapeutic procedures and decreasing insurance funds. The solution out of this dilemma is seen in specialization and decentralization combined with extended communication and collaboration, also called shared care paradigm. This is bound to result in a paradigm change for providing health services from organization-centered to process-controlled care. This concept is widely known as eHealth. And the patient, who needs to be moved to the center of al medical and welfare workflow processes, needs to be

empowered to support the care management in a way that leaves him / her back as a satisfied citizen.

In the future, the level of specialization and decentralization will further grow towards individualized care according to health status and process needs of the single citizen, i.e., personal health or pHealth. In this context, prevention and monitoring of -especially chronically diseased- patients play an increasing role. Shared care at any level needs comprehensive support by information and communication technology ICT. Those ICT systems have to be specialized and decentralized, too. For providing seamless care, the systems have to be connected in an intelligent and comprehensive way. For implementing the new care paradigms, i.e. advanced health telematics linked to telemedicine, need to be introduced at regional, national and global level.

Currently, a paradigm shift can be observed towards a new generation of personal health information systems with process-controlled, service-oriented, context-sensitive, semantically interoperable information and communication architectures. These systems require open, highly flexible application systems, which are individually tailored regarding both the cared and the caring party. Such applications cannot be pre-manufactured anymore, but must be dynamical and adaptable to the actual requirements and needs. That way the Autonomous Computing for realizing self-organizing systems will be introduced. Mobile Computing for realizing accessibility and Pervasive Computing already allows independency from any location while providing specific services (e.g. telemedicine). The combination of the aforementioned technology paradigms leads to Ubiquitous Computing, which is bound to other paradigms and trends such as health grids. Personal health requires an adequate legal framework and the new orientation of traditional organizational patterns.

Both concepts of eHealth and pHealth see the citizen in the center. Patient data cards are first line communication tools. They can hold medical data and improve the accessibility to information on healthcare services as well as to personal healthcare data. Thus they enable better health provision.

At present, smart cards are widely used as identification tokens not only in healthcare. Many European countries are scheduling the introduction of citizen cards, insurance cards, or just electronic ID cards. The EHIC (European Health Insurance Card) is being introduced in all countries of the European Union. As the EHIC contains respective information item just in written form (mostly on the back side of existing health cards), an electronic version called eEHIC is under discussion. A task force within CEN shall develop a specification for enabling an electronic exchange of relevant data needed for providing healthcare services to all EU citizens regardless in which EU country they actually stay. Both possession and appropriate use of cards can, and will, empower citizen playing their role as an important part(ner) of healthcare and welfare workflow.

Involving patients requires -besides financial engagement- also a change of thinking. It is more than "just another topic on the agenda"; it is a cultural change. On the other hand, involving patients is more than a goodwill action of the governments; it is a necessity in order for patients to take their share in the healthcare process concerning responsibility and costs.

Confidence in and acceptance of the healthcare systems depend on the citizens' awareness, which needs yet to be raised. Citizens have to realize that healthcare is a concern of theirs at all times. The shift from acute healthcare to life-long-health and a preventive healthcare has to be enforced and speeded up. Citizens shall and will have to form alliances and associations to advocate their interests.

The institutions have a responsibility to provide reliable up-to-date information free of stakeholders' interests to the citizen. Security tokens -such as health cards- can play a vital role for securely accessing sensitive personal health related data. Wholehearted marketing strategies -such as EHIC- are required. Experiences made in one country cannot be transferred; ethical and cultural differences have to be taken into account. Special user groups have to be taken care of at the earliest possible point of time.

## 4. Conclusions

Shared care solutions all over the world have to be based on trustworthy and reliable communication and application security services. Smart cards in general, Patient Identification Cards (PIC), Patient Data Cards (PDC), Health Insurance Cards (HIC), and Health Professional Cards (HPC) play an important role; either as a personal ID token for access purposes, as a professional ID token describing structural roles, or as a health data carrier. Cards have an impact on the related security infrastructure, certification of processes, process interoperability (workflow), and certification of state and relations of principals in longer terms [33]. This is especially true for the upcoming fast development on Electronic Health Record (EHR) architectures, their requirements, their design, their policy details, and their instantiation and implementation strategies.

Citizen and patient involvement and empowerment are definitely based on awareness, confidence, and acceptance. An adequate level of awareness can be achieved by providing a respective level of information, education, and related training measures. This will lead to confidence with regard to card technology. In daily use and based on the patients' respective behavior, the level of acceptance is going to grow leading to an even higher level of awareness at the end of the day.

The criteria / factors which determine the citizen's acceptance of these technologies and methods and the citizen's interest in these topics need to be further investigated and accurately discussed. As this is not a task for a single nation, international organizations took over responsibility for investigating the circumstances for developing patient involvement and patient empowerment strategies world-wide.

Ethical aspects are the very basis for all empowerment strategies [11]. The more information citizens and patients have regarding different procedures and processes in healthcare, the more will they able to significantly play their dedicated role within a profitable doctor-patient partnership. Cards can and will contribute by allowing citizens and patients to get controlled access to administrative and medical data stored either on a card or in the network. And the card holders can determine who shall have access to these information items.

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## References


[1] Koyama W. Lifestyle Change Improves Individual Health and Lowers Healthcare Costs. Methods of Information in Medicine 2000 39 3: 229-232.

[2] Blobel B. *Analysis, Design and Implementation of Secure and Interoperable Distributed Health Information Systems.* Series "Studies in Health Technology and Informatics" Vol. 89. IOS Press, Amsterdam 2002.

[3] Blobel B, Pharow P (Edrs.) Advanced Health Telematics and Telemedicine. The Magdeburg Expert Summit Textbook, pp. 21-28. Series "Studies in Health Technology and Informatics" Vol. 96. IOS Press, Amsterdam 2003

[4] UNO Resolution on „Standard rules on equal chances for the disabled". New York, 1994. http://www.un.org/documents/ga/res/48/a48r096.htm (last accessed April 15th, 2008)

[5] WHO Regional Office „Principles on the rights of patients in Europe". Geneva, 1994. http://www.who.int/genomics/public/eu_declaration1994.pdf (last accessed April 15th, 2008)

[6] WHO "World Alliance for Patient Safety". Geneva, 2004. http://www.who.int/patientsafety/en/brochure_final.pdf (last accessed April 15th, 2008)

[7] Gesetz zur Modernisierung der gesetzlichen Krankenversicherung (SHI Modernization Act), Bundesgesetzblatt Jahrgang 2003 Teil 1 Nr. 55. Issued in Bonn on November 19th, 2003. In German. http://217.160.60.235/BGBL/bgbl1f/bgbl103s2190.pdf (last accessed April 15th, 2008)

[8] The Irish Society for Quality and Safety in Healthcare: Lets Talk …Your Health is important make it personal. A guide to becoming more actively involved in your healthcare. http://www.isqsh.ie/ssi/_file.asp?id=2&save=1 (last accessed April 15th, 2008)

[9] Jürg WA. Patienten - Empowerment aus systemischer Sicht; Managed Care 4-99. Verlag Rosenfluh Publikationen. In German. http://www.hdpev.de/files/JurgWilhelmEmpowerment.pdf (last accessed April 15th, 2008)

[10] Birkmann C, Dumitru RC, Prokosch HU. Evaluation of Health-related Internet Use in Germany. Methods of Information in Medicine 2006 45 4: 367-376.

[11] Kluge EHW. Medical Narratives and Patient Analogs: The Ethical Implications of Electronic Patient Records. Methods of Information in Medicine 1999 38 4: 253-259.

[12] Härter M. Erfahrungsbericht aus dem Modellprojekt „Der Patient als Partner im medizinischen Entscheidungsprozess", AQS-Workshop. 26.11.2003, Freiburg, 2003. In German. http://www.patient-als-partner.de (last accessed April 15th, 2008)

[13] Ball MJ, Douglas JV. Redefining and Improving Patient Safety. Methods of Information in Medicine 2002 41 4: 271-276.

[14] International Alliance of Patients' Organizations (IAPO), http://www.patientsorganizations.org (last accessed April 15th, 2008)

[15] IAPO Policy Statement on Patient Involvement, http://www.patientsorganizations.org/showarticle.pl?id=590&n=962 (last accessed April 15th, 2008)

[16] Demski H, Hildebrand C, Engelbrecht R, Birkmann C. DIABCARD, the portable patient record – pursuing routine use. In: Blobel B et al. (Eds.) Contributions of Medical Informatics to Health. Berlin, 2004.

[17] Mechtler, R. DIABCARD Overall Validation. Report. European Commission, June 2000.

[18] Van der Lei J: Closing the Loop between Clinical Practice, Research, and Education: The Potential of Electronic Patient Records. Methods of Information in Medicine 2002 41 1: 51-54.

[19] Pharow P, Blobel B. Security Infrastructure Requirements for Electronic Health Cards Communication. In: Engelbrecht R, Geissbuhler A (Edrs.): Connecting Medical Informatics and Bio-Informatics. Proceedings of MIE 2005. Series "Studies in Health Technology and Informatics" Vol. 116. IOS Press, Amsterdam 2005.

[20] Faber MG. Design and Introduction of an Electronic Patient Record: How to Involve Users? Methods of Information in Medicine 2003 42 4: 371-375.

[21] Blobel BGME. Advanced EHR Architectures – Promises or Reality. Methods of Information in Medicine 2006 45 1: 95-101.

[22] CEN ENV 13729 "Health informatics - Secure user identification – Strong authentication using microprocessor cards (SEC-ID/CARDS)", 1999.

[23] ISO 21549 "Health Informatics – Patient health card data", 2004. http://www.iso.org. (last accessed April 15th, 2008)

[24] CEN EN 13729rev "Health informatics - Secure user identification – Strong authentication using microprocessor cards", 2006.

[25] ISO 21549 "Health Informatics – Patient health card data, part 8 Links", 2006 (working draft version).
[26] Pharow P, Hildebrand C, Blobel B. The Changing Role of Patient and their Health Cards in Integrated eHealth Environments. In: Reichert A, Mihalas G, Stoicu-Tivadar L, Schulz S, Engelbrecht R (Edrs.): Integrating Biomedical Information: From eCell to ePatient, pp. 70-74. IOS Press and Akademische Verlagsgesellschaft Aka GmbH, Berlin; 2006.
[27] Engel K, Kuziela H, Blobel B, Pharow P. Security Services for the HemaCAM Project. In: Engelbrecht R, Geissbuhler A (Eds.): Connecting Medical Informatics and Bio-Informatics. Proceedings of MIE 2005. Series "Studies in Health Technology and Informatics" Vol. 116. IOS Press, Amsterdam, 2005.
[28] Hildebrand C, Pharow P., Engelbrecht R, Blobel B, Savastano M, Hovstø A. BioHealth – The Need for Security and Identity Management Standards in eHealth. In: Hasman A, Haux R et al (eds) Studies in Health Technology and Informatics IOS Press, Amsterdam 2006
[29] EU project BioHealth "Security and Identity Management Standards in eHealth including Biometrics - Specific Requirements having an Impact on the European Society and on Standardization". Scheduled 2006 - 2008. http://www.bio-health.eu (last accessed April 15th, 2008)
[30] Jahn K, Gartig-Daugs A, Nagel E. Telemedicine and e-Health - Electronic Health Records within Integrated Care in Germany. Telemedicine and e-Health. April 1, 2005, 11(2): 146-150.
[31] Loukanova S, Bridges J. Measuring patient empowerment in the general community. Paper presented at the annual meeting of the Economics of Population Health: Inaugural Conference of the American Society of Health Economists, Madison, WI, USA, 2006
[32] The Specifications of the German Health Card (Elektronische Gesundheitskarte). http://www.gematik.de (last accessed April 15th, 2008)
[33] The European Electronic Signature Standardization Initiative (EESSI) – an Industry Initiative in Support of the European Directive on Electronic Signature. http://www.ictsb.org/EESSI_home.htm (last accessed April 15th, 2008)

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# The Value of Personal Health Records A Joint Position Statement for Consumers of Health Care[1]

American Health Information Management Association
American Medical Informatics Association

## 1. Position

The American Health Information Management Association (AHIMA) and the American Medical Informatics Association (AMIA) advocate empowering individuals to manage their healthcare through the use of a personal health record (PHR). The PHR is a tool for collecting, tracking and sharing important, up-to-date information about an individual's health or the health of someone in their care. Using a PHR will help people make better health decisions and improves quality of care by allowing them to access and use information needed to communicate effectively with others about their healthcare.

## 2. Basic Principles

- Every person is ultimately responsible for making decisions about his or her health.
- Every person should have access to his or her complete health information. Ideally it should be consolidated in a comprehensive record.
- Information in the PHR should be understandable to the individual.
- Information in the PHR should be accurate, reliable, and complete.
- Integration of PHRs with EHRs of providers allows data and secure communication to be shared between a consumer and his or her health care team.
- Every person should have control over how their PHR information is accessed, used and disclosed. All secondary uses of PHR data must be disclosed to the consumer, with an option to opt-out, except as required by law.
- PHR products should be certified by CCHIT to comply with data standards, include a minimum data set, identify each data's source, and meet security criteria consistent with HIPAA

[1] Because the use of personal health records is an issue of importance to both organizations, AHIMA and AMIA collaborated on the development of this joint position statement, published on 2-1-2007.

- The operator[2] of a PHR must be accountable to the individual for unauthorized use or disclosure of personal health information. The consumers should be notified immediately of breeches in security that could lead to disclosure of personal health information.
- A PHR may be separate from and does not normally replace the legal medical record of any provider.
- Privacy protection of PHR data should follow the data. PHR data must not be used in any discriminatory practices.

## 3. Questions and Answers

### *3.1. Why should everyone have a PHR?*

We believe that all individuals should be able to readily access, understand, and use their personal health information. A PHR allows individuals to be more active partners in their healthcare, and gives them up-to-date information when and where they need it. A PHR provides a single, detailed and comprehensive profile of a person's health status and healthcare activity. It facilitates informed decisions about the care of the individual. It may also reduce duplicate procedures or processes – such as repeated lab tests and x-rays – saving time and money. A PHR helps people prepare for appointments, facilitates care in emergency situations, and helps track health changes.

### *3.2. What Media should you Use for a PHR?*

We encourage individuals to begin tracking their health information in whatever format works best for them, even if the choice is paper. We recommend that individuals use an electronic media to facilitate a timely, accurate, and secure exchange of information across healthcare institutions and providers. PHR information should always be stored in a secure manner just as you would store other confidential personal information such as financial information.

### *3.3. How can an Individual Choose a PHR Supplier?*

Individuals can create their own PHR, or may be offered one by a variety of sources, such as a healthcare provider, insurer, employer or a commercial supplier of PHRs. Each supplier has different policies and practices regarding how they may use data they store for the individual. Study the policies and procedures carefully to make sure you understand how your personal health information will be used and protected. Policies to look for include privacy and security; the ability of the individual, or those they authorize, to access their information; and control over accessibility by others. If the PHR contains the same information that the doctor has seen, it has more usefulness for tracking purposes than information from insurance forms. For example, insurance claims information may list the diagnosis or medication but not the details (for example, actual blood pressure reading or dose of the medication taken).

[2] An "operator" could be a healthcare provider, health plan, commercial supplier, government agency, employer, union, fraternal order, and so forth.

### *3.4. What should a PHR Contain?*

Broader than a medical record, the PHR should contain any information relevant to an individual's health. In addition to medical information such as test results and treatments, a PHR may include diet and exercise logs or a list of over-the-counter medications. A PHR should contain the following information:

- Personal identification, including name and birth date
- People to contact in case of emergency
- Names, addresses, and phone numbers of your physicians, dentists, and specialists
- Health insurance information
- Living wills, advance directives, or medical power of attorney
- Organ donor authorization
- A list and dates of significant illnesses and surgical procedures
- Current medications and dosages
- Immunizations and their dates
- Allergies or sensitivities to drugs or materials, such as latex
- Important events, dates, and hereditary conditions in your family history
- Results from a recent physical examination
- Opinions of specialists
- Important tests results; eye and dental records
- Correspondence between an individual and his or her provider(s)
- Current educational materials (or appropriate web links) relating to one's health

## *3.5. Where Individuals should Begin?*

A good place to begin is with a visit to www.myPHR.com (a site provided as a free public service by AHIMA) for further information on creating and managing a PHR. We suggest that people find out if their healthcare providers, employer, insurers, or another individual or organization offers a PHR. If an individual needs to obtain copies of medical records themselves, they can contact doctors' offices or each facility where they have received treatment.

Each person can create a PHR at his or her own pace, perhaps starting with the next medical visit. The important thing is to get started.

**About AHIMA**

The American Health Information Management Association (AHIMA) is the premier association of health information management (HIM) professionals. AHIMA's 50,000 members are dedicated to the effective management of personal health information needed to deliver quality health care to the public. Founded in 1928 to improve the quality of medical records, AHIMA is committed to advancing the HIM profession in an increasingly electronic and global environment through leadership in advocacy, education, certification, and lifelong learning. URL: http://www.ahima.org

**About AMIA**

The American Medical Informatics Association (AMIA) is an organization of 3,500 health professionals committed to informatics who are leaders shaping the future of health information technology and its application in the United States and 41 other nations. AMIA is dedicated to the development and application of informatics in support of patient care, teaching, research, and health care administration and public policy. URL: http://www.amia.org

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