Cambridge History of Medicine

EDITORS: CHARLES WEBSTER and CHARLES ROSENBERG

AIDS and contemporary history

The advent of AIDS has led to a revival of interest in the historical relationship of disease to society. Now, after ten years, there is a new consciousness of AIDS and history, and of AIDS itself as an historic event. This is the starting-point of this new collection of essays.

Its twin themes are the 'pre-history' of the impact of AIDS, and its subsequent history. The section on the 'pre-history' of AIDS includes articles which analyse the contexts against which AIDS should be measured. The second section – on AIDS as history – presents chapters by historians and policy scientists on such topics as British and US drugs policy, the later years of AIDS policies in the UK, and the development of AIDS as a political issue in France. A final chapter looks at the archival potential in the AIDS area. As a whole the volume demonstrates the contribution which historians can make in the analysis of near-contemporary events.

Cambridge History of Medicine

EDITED BY
CHARLES WEBSTER
Reader in the History of Medicine, University of Oxford,
and Fellow of All Souls College

CHARLES ROSENBERG
Professor of History and Sociology of Science,
University of Pennsylvania

For a list of titles in the series, see end of book

AIDS and contemporary history

EDITED BY

VIRGINIA BERRIDGE

AND

PHILIP STRONG

AIDS Social History Programme, London School of Hygiene and Tropical Medicine

CAMBRIDGE
UNIVERSITY PRESS

PUBLISHED BY THE PRESS SYNDICATE OF THE UNIVERSITY OF CAMBRIDGE
The Pitt Building, Trumpington Street, Cambridge, United Kingdom

CAMBRIDGE UNIVERSITY PRESS
The Edinburgh Building, Cambridge CB2 2RU, UK
40 West 20th Street, New York NY 10011–4211, USA
477 Williamstown Road, Port Melbourne, VIC 3207, Australia
Ruiz de Alarcón 13, 28014 Madrid, Spain
Dock House, The Waterfront, Cape Town 8001, South Africa

http://www.cambridge.org

First published 1993
First paperback edition 2002

A catalogue record for this book is available from the British Library

Library of Congress Cataloguing in Publication data
AIDS and contemporary history / edited by Virginia Berridge
and Philip Strong.
p. cm. – (Cambridge history of medicine)
Includes index.
ISBN 0 521 41477 6 (hardback)
1. AIDS (Disease) – History. I. Berridge, Virginia, 1946– .
II. Strong, Philip, 1945– . III. Series.
RC607.A26A3455517 1993
362.1'969792'009–dc20 92-14276 CIP

ISBN 0 521 41477 6 hardback
ISBN 0 521 52114 9 paperback

Contents

I The pre-history of AIDS

II AIDS as history

Notes on contributors

WARWICK ANDERSON is a medical doctor and Assistant Professor in the History of Science Department at Harvard. His research interest is in the historical development of health policy and medical care. In addition to this, he is the principal investigator for an epidemiological and ethnographic study of the recourse to complementary therapies by patients with HIV infection.

VIRGINIA BERRIDGE is Senior Lecturer in History at the London School of Hygiene and Tropical Medicine and Co-Director of the AIDS Social History Programme there. She is currently researching the policy history of AIDS in the UK. Her publications include *Opium and the People: Opiate Use in Nineteenth-Century England* (1987) (main author); 'Health and disease 1750–1950', in the *Cambridge Social History of Britain* (ed. F. M. L. Thompson) (1990) and *Drugs Research and Policy in Britain: A Review of the 1980s* (1990).

EWAN FERLIE is currently Associate Director of the Centre for Corporate Strategy and Change, University of Warwick. He was previously Research Fellow at the Personal Social Services Research Unit, University of Kent. His wide range of research interests in NHS management includes: innovation processes, the management of change and strategic management in the context of managed competition.

JANET FOSTER is a professional archivist now working as a consultant. She has considerable experience with medically related archives, working for St Bartholomew's Hospital and the Wellcome Institute for the History of Medicine before joining the AIDS Social History Programme at the London School of Hygiene and Tropical Medicine. Her publications include *British Archives: A Guide to Archive Resources in the UK* (1989) and *AIDS Archives in the UK* (1990).

VICTORIA A. HARDEN is the Director of the National Institutes of Health Historical Office and the DeWitt Stetten, Jr Museum of Medical Research. In 1989 she co-chaired a conference 'AIDS and the Historian', whose proceedings were published in 1991. The author of two books and a number of articles, Dr Harden has written about federal biomedical research policy in the US, the history of infectious diseases and twentieth-century biomedical research instrumentation. Her current interests include the history of AIDS at NIH and twentieth-century biomedical research instrumentation.

JANE LEWIS is a Professor of Social Policy at the London School of Economics. She is the author of: *Women and Social Action in Victorian and Edwardian England* (1991); with D. Clark and D. Morgan, *Whom God Hath Joined: The Work of Marriage Guidance, 1920–1990* (1992); with Barbara Meredith, *Daughters Who Care. Daughters Looking after Mothers at Home* (1988); and *What Price Community Medicine?* (1986).

ILANA LÖWY is at the Institute National de la Santé et de la Recherche Médicale (INSERM). Her interest in the relationships between biological knowledge and medical practice has led her to studies in the history of bacteriology, immunology and cancer research and to investigation of the epistemological thought of Ludwik Fleck. She has recently published *The Polish School of Philosophy of Medicine: From Tytus Chalubinski (1820–1889) to Ludwik Fleck (1896–1961)* (1990).

WILLIAM MURASKIN, PhD, is Associate Professor of Urban Studies, Queens College, City University of New York. His recent publications include 'Individual rights versus the public health: the controversy over the integration of retarded hepatitis B carriers into the New York public school system', *Journal of the History of Medicine and Allied Sciences* (1990) and 'The silent epidemic: the social, ethical, and medical problems surrounding the fight against hepatitis B', *Journal of Social History* (1988). He is currently working on a book entitled *Scientists in Service to Humanity: A History of the International Task Force for Hepatitis B Immunization and the Fight to Eradicate Liver Cancer.*

DENNIS RODRIGUES is Executive Assistant to the Director of the National Institutes of Health Historical Office and the DeWitt Stetten, Jr Museum of Medical Research. Before joining this office, he was a laboratory research technician and, later, a policy analyst who helped to establish the NIH Office of AIDS Research. Mr Rodrigues has written numerous internal NIH policy studies and is a co-author of seventeen scientific papers. His current research interests include the history of AIDS at NIH and twentieth-century biomedical research instrumentation.

MONIKA STEFFEN is a researcher in political sciences at the National Centre of Scientific Research (CNRS). She is author of publications on public health policies in France, including international comparisons. At present, she is researching a comparison of AIDS policies in four European countries.

JOHN STREET is a Lecturer in Politics and Director of the Centre for Public Choice Studies at the University of East Anglia. He has written extensively on British AIDS policy and is the co-author (with John Greenaway and Steve Smith) of *Deciding Factors in British Politics* (1992).

PHILIP STRONG is Co-director of the AIDS Social History Programme and Senior Lecturer in Sociology in the Department of Public Health and Policy, London School of Hygiene and Tropical Medicine. He is the author of *The Ceremonial Order of the Clinic* (1979), editor and co-author of the eight-volume series *Health and Disease* (1985) and co-author of *The NHS: Under New Management* (1990).

BRIDGET TOWERS is a Senior Lecturer at Kingston Polytechnic in the Faculty of Human Sciences where she teaches social policy and is a member of the Gender Studies Group. Her research and publications are in the field of the history of medicine, with a particular focus on the politics of international health organisations. Her current work is a mixture of empirical research on the impact of policy changes on the occupational identity and morale of district nurses, and historical research on the disappearance of the concept of convalescence in British health care provision.

JEFFREY WEEKS is Professor of Social Relations at Bristol Polytechnic. He is the author of numerous articles and books on various aspects of the social regulation of sexuality. These include *Sex, Politics and Society* (1981), and *Against Nature: Essays on History, Sexuality and Identity* (1991).

PAUL WEINDLING is Senior Research Officer at the Wellcome Unit for the History of Medicine, University of Oxford. He is the author of *Health, Race and German Politics between National Unification and Nazism, 1820–1945* (1989). He is currently researching into aspects of international health between the First and Second World Wars.

Acknowledgements

The editors would like to acknowledge the Nuffield Provincial Hospitals Trust for funding the AIDS Social History Programme at the London School of Hygiene and Tropical Medicine and the conference 'AIDS and Contemporary History' in April 1990 from which the proposal for this book stemmed. Virginia Berridge wishes to thank Philip Bean and David Whynes for their permission to reprint a substantially revised version of 'AIDS and British drug policy' which appeared in their edited collection *Policing and Prescribing: the British System of Drug Control* (London 1991). Warwick Anderson is grateful to the editors of the *American Journal of Public Health* for their permission to republish his paper 'The New York needle trial: the politics of public health in the age of AIDS'. Both editors wish to thank Ingrid James for unfailing secretarial support, and Diana LeCore for compiling the index.

Introduction AIDS and contemporary history

VIRGINIA BERRIDGE

There is a different historical consciousness around AIDS at the end of ten years. AIDS now has its own history, rather than borrowing from the more distant past. Surveys of the recent past, looking back over a decade, are common. There is a realisation, too, that understanding AIDS requires an assessment of the 'larger agenda' of health, social and science policy development in the post-war period. The impact of the disease cannot be assessed without knowing something of this 'pre-history'. This book is therefore framed around the twin areas of AIDS as history and the pre-history of the disease. Its concern is very much with AIDS as an issue in contemporary history and with the perspectives on the history of post-war health policy which it has revealed.

The purpose of this introductory chapter is not just to survey AIDS as a problem in contemporary history, but to reflect on the changing relationship of AIDS and history over the past ten years. For even in its early stages, the disease brought history in its train. The function of the discipline was different at that time. Much historical commentary aimed to point a 'lesson of history'. Its concern was to draw parallels with the distant past rather than to locate AIDS in its immediate pre-history. The form of history has therefore changed over time. It has shifted from far distant events to those of only a few years ago. The function of history, too, has shifted. Three functions of historical policy writing can broadly be identified: 'policy relevant' history feeding in to current policies or used in forecasting future developments; 'recreating the past' for its own sake, academic 'voyeurism' or journalism; and policy analysis, the understanding of past events according to particular theoretical models and empirical understanding, analysing the past without specific current policy intent (although the insights provided may feed into perceptions of the present). The relationship between AIDS and history has developed away from the first function, the 'lesson of history', through journalism and towards historical policy analysis. In doing so, it has brought a realisation of the strengths of the historical approach, what makes it unique and appropriate for the analysis of recent, as well as more distant, events.

AIDS, epidemic disease and the 'lesson of history'

Let us begin by tracing the 'history of AIDS and history'. The initial role of history was very much that of the first function of 'policy relevant' history. The 'lesson of history' was to the fore. The novelty and shock of a life-threatening infectious disease of potentially epidemic proportions in the late twentieth century led to a search for explanatory models from the past with some degree of predictive power. How had society reacted to and dealt with past epidemics? Could the past give a clue to the end of this particular disease story? What forms of reaction were appropriate? The initial historical input focused on three broad areas: the role of epidemic disease in past societies, in particular the association between disease and 'moral panic' or disease and stigmatised minorities; the historical record in the area of sexually transmitted disease, in particular the traditions of voluntarism and confidentiality in this area in Britain; and more general questions of ends and means in public health policy, focusing on practices such as quarantine and notification, and contributing to the classic public health debate between the rights of the individual and the good of society. Papers and collected editions on these themes proliferated.[1]

Nor was historical consciousness confined to historians. The annual international AIDS conference, an enormous gathering, early on developed a history strand amid a primarily clinical, scientific and epidemiological focus. Historians of 'relevant' areas such as cholera and plague suddenly found their work and thoughts of interest to participants in AIDS conferences, actively seeking the 'lesson of history'. This lesson was mediated by different national cultures. In France, for example, the earlier history of regulation in the area of sexually transmitted diseases was one which included central state regulation in particular of prostitution. It was this national history which entered the French debates around AIDS in the 1980s. The United States, perhaps in line with its own pluralist and federal structures, saw a plurality of competing 'lessons' around the issues of compulsion and confidentiality.[2] But in Britain the 'lesson of history' almost without exception stressed a voluntaristic, non-punitive and confidential response. The historian Roy Porter's editorial in the *British Medical Journal* in 1986 headlined 'History says no to the policeman's response to AIDS' was a high point in historical judgement on the present, drawing on analogies from the history of public health in relation to civil liberties and on the British example in the area of sexually transmitted diseases (STDs).[3]

These historical arguments were of some policy significance. Two key protagonists in early AIDS policy making in Britain, Professor Michael Adler at the Middlesex Hospital and Sir Donald Acheson, Chief Medical Officer at the Department of Health, had a keen interest in historical precedent.[4] The reports of the Chief Medical Officer in the early AIDS years were consciously historical, citing parallels between AIDS and the great nineteenth-century battles against disease.[5] History was used both to construct and defend a liberal consensus around AIDS. The 'lesson of history' came into the debates in 1985 about whether AIDS should be made a compulsorily notifiable disease (it was not); and in the general defence of a liberal line. Acheson in his evidence to the Commons Social Services Committee hearing on AIDS in 1987 cited the historical record as a prime reason for avoiding a punitive response to AIDS.[6]

AIDS as a 'chronic disease' and history

The historical arguments and analogies were of importance in early British policy formation. AIDS was an 'open' policy area and it was possible for policy to be directly influenced in ways which would be more unusual in an established policy arena. But the early period of AIDS as an 'epidemic disease' passed and with it passed the role of epidemic history. AIDS policy development in Britain over the past decade has passed through three stages: an initial period from 1981 to 1986 of surprise and shock, with relatively little official action, succeeded in 1986–7 by a brief period of 'war-time emergency' when politicians publicly intervened and AIDS was officially established as a high level national emergency.[7] 'Epidemic history' fitted well into these initial stages and was itself an active policy force in the British context. But from 1987 onward, these two initial 'heroic' phases have been followed by a calmer period, by what has been termed the 'normalisation' of the disease and of the public reaction to it. The model of chronic rather than epidemic disease has come to the fore.[8] History has been less of an active policy force; and the historical analogies used to understand the disease have themselves changed to accommodate this change in perception. Take, for example, a piece by Charles Rosenberg in a 1989 issue of *Daedalus*. Distinctly post-heroic and post-epidemic in tone, it notes the range and stages of policy choices in an epidemic. Rosenberg cites the 'chronic disease' model of tuberculosis, which, although far more widespread in the nineteenth century, did not elicit the moral and political pressure for immediate action as did yellow fever or cholera.[9] How and why the chronic disease model came so swiftly to establish hegemony is a valid area of investigation. In policy terms AIDS was assimilated to the pre-existing dominant twentieth-century models of disease, those of chronic degenerative, not epidemic infectious disease. The work of historians played little part in challenging the hegemony of that perspective. For 'the lesson of history' in both the later and the early stages of AIDS policy development mirrored the preconceptions of the present.

'Relevant history' of this type has its dangers. In an open policy situation, the case with AIDS in the first half of the 1980s, history could play a practical rather than a symbolic role. How far that role was justified was a different matter. For what lay behind this form of historical intervention was a Whiggish assumption that there was indeed a 'lesson of history' which could be learnt, that the past could provide a blueprint for a present-day policy reaction. Historical reaction was predicated on the assumptions of the present. The implication was that history was incontrovertible 'fact' rather than a welter of differing interpretations, themselves in turn historically specific. The belief that historical evidence was some higher form of truth, although useful in establishing particular policy positions, down-played some of its subtler strengths of analysis.

This was an approach which accorded well with the ethos of the time. In the United States, as Elizabeth Fee and Daniel Fox have commented, the study of history had seemed less relevant prior to AIDS; the revival of history as a policy science came with the disease.[10] In the UK, the situation was somewhat different. The status of history as what one commentator had called a 'profoundly ideological subject' had revived even prior to AIDS.[11] In the 1980s, the initiative had come from the right rather than the left. While history on the left, a dynamic force in the 1960s and early 70s, had often seemed on the defensive, or preoccupied with its own historiography and with internal debate, history on the right increasingly made the running in relation to practical policy issues.[12] The demand for a return to nineteenth-century 'self-help' and to 'Victorian values' and the debates round the place of history in the British schools national curriculum may be cited as particular examples. Discussion round this latter issue had also centred on the role of fact in history and the 'lesson of history' approach. In Britain, therefore, the early relationship between AIDS and history continued and extended the existing interface between policy and history. And in Europe in general, especially eastern Europe, the 'lesson of history' seemed particularly appropriate in the late 1980s as a series of revolutions overturned communist governments. In Czechoslovakia for example, radicalism was built around historical example; and parallels with the revolutions of 1848 were commonly made. In general, then, there was a heightened European sense of the historical relationships of policy change in the 1980s. Such consciousness can have its dangers. As Pat Thane has commented, it looks at events through the 'wrong end of the telescope', taking little account of the necessity of understanding past events in the very different context of their time.[13] Other historians too have commented on the dangers of 'presentism'. Hugh Trevor Roper put it baldly; historians were in danger of being 'great toadies of power', simply justifying, and not analysing, or challenging dominant perspectives.[14]

The focus of this volume is not the 'lesson of history', but a different form of historical analysis. At the end of the first decade of epidemic, different types of history have come to the fore. The notion of AIDS itself as history is more prominent and with it the potential role of the 'contemporary history' of health policy in general. Nonetheless historical analogy should not be discounted. Such historical intervention is valuable in challenging dominant preconceptions and in locating contemporary reactions in their context. As Shirley Lindenbaum has argued, 'history as background' has a useful role to play. She has pointed, for example, to the historic specificity of stigma in relation to diseases such as leprosy; and to the 'cultural construction' of the individual liberty/public good dichotomy which is now presented as at the heart of the public health debate.[15] The particular focus of this volume is on two areas of historical analysis – the 'contemporary history' of AIDS and what we call the 'pre-history' of the disease. AIDS itself is a study in history; and the significance of almost contemporary events cannot be understood without locating them in context. We cannot assess the impact of AIDS across a whole range of policy arenas – from research policy to drug policy, from the church to the gay response – without analysing developments in post-war policy in those areas and, in particular, the issues which have been of importance since the 1960s and 70s. AIDS has underlined the lack of historical study of many areas of health and social policy in recent decades.

A growing body of work is focusing on the concept of 'AIDS as history', from a variety of different perspectives. One early example was Dennis Altman's *AIDS and the New Puritanism* (1986), which documented and analysed the early gay response to the crisis.[16] This has been joined by other histories. Gerald Oppenheimer, for example, has seen AIDS as a case study in the construction of disciplinary ownership of an issue and has analysed the role played by epidemiologists and virologists in the scientific construction of AIDS.[17] Daniel Fox, Patricia Day and Rudolf Klein have compared the development of AIDS policies in Sweden, the UK and USA.[18] The form and functions of such histories has varied – from a brief reconstruction of the early history of the Terrence Higgins Trust, to an analysis of the pre- and contemporary history (and possible future) of the Federal Drugs Agency (FDA) and drug regulation in the United States under the impact of AIDS.[19] At the end of the first decade of the disease, even ostensibly non-historical analysis routinely includes a survey of particular histories of the past decade and before. Papers on volunteering and AIDS; on doctors and AIDS patients; and on the issues for reproductive freedom raised by AIDS published in a recent volume located their analysis in the histories both of contemporary events and of preceding decades.[20] The journal *AIDS Care* had a historical survey of the past ten years as part of its tenth anniversary issue.[21] Professor Tony Coxon, a sociologist and leading AIDS researcher, introduced his remarks at an AIDS conference aimed at bringing social scientists and policy makers together with a history of the Economic and Social Research Council's involvement in the area.[22] The examples are legion.

Such reflectiveness is a natural process. The new historical face of AIDS has continued to have a number of functions; and its practitioners have also been varied. Policy relevance as well as policy analysis has continued to be the order of the day; and some surveys have adopted what Roy Porter has called a 'heroes and villains' approach, which tends to ignore the social and structural underpinning of events. The American journalist Randy Shilts's history of the early years of the AIDS epidemic in the United States, *And the Band Played On* has been criticised for the emphasis it places on personal culpability rather than the slowness and ineptitude of the American Federal state.[23] Journalists have in fact played a particular role in writing the 'contemporary history' of AIDS. Several, both in the United States and in Britain, used their vantage point on events to produce speedy accounts of the initial crisis.[24] Other accounts have derived from a different mix of perspectives. Science and history proved a powerful combination in M. D. Grmek's *History of AIDS*.[25] Contributions have also come from sociology, from anthropology (where the interest in cultural formation and change over time has meshed with the historical approach) and from political science.[26] In Britain, the annual meeting and proceedings of the Social Aspects of AIDS conference have provided not just a vantage point for British sociology, but also a wealth of source material for contemporary history.[27] There are thus a variety of disciplinary approaches mingling in the recent history fold. Added to them is what can be termed 'activist contemporary history'. There is concern that the early dimensions of the voluntary and largely gay response, subsequently overlain by one which attracted statutory funding, which was professionalised, normalised and non-gay, may be 'hidden from history'. There has been a concern to document this early response before memories and participants are lost.[28] Such historical consciousness can also have its dangers. 'History from below' for AIDS, as more generally, runs the risk of presenting an alternative 'official history' also cast in the heroes and villains mould.[29] The 'invention of tradition' can also be a feature of the reconstruction of the recent past.

Given the incipient vitality of the field, what can historians contribute? It might indeed be asked what the particular strengths of the discipline are. Some policy scientists have stoutly maintained that the historian has no business in dabbling with contemporary events.[30] So why is AIDS a problem in contemporary history? Three broad strengths can be presented for consideration: the historian's sense of chronology; the historical sense of continuity as well as change; and, within an overall chronology, a synthetic and critical ability to interweave and assess different forms of source material and different levels of interpretation. Chronology may not be everything and much fundamental work in history cannot be done within a purely chronological framework. Nonetheless, academic history, more than any other social science, has made a disciplinary specialty of the passage of time. Another potential strength lies in the historian's implicit cynicism about the routine proclamations of a new departure in policy. Historians, more than most other social scientists, have the capacity to locate policy change in past practice, to seek out antecedents and tendencies which feed into present policy development. At its worst, this ability can prove an obsessive desire to show that nothing ever changes, to deny the relevance of individual or collective effort. At its best, it provides a powerful means of setting policy development in its proper context. For AIDS, for example, supposedly new policies such as those in research or illegal drugs, turn out to possess deep roots in the past. The final strength of the historical approach lies in its generalising ability both in terms of methodology and of theoretical approach. The relative atheoreticity of the subject has been a matter of comment from other disciplinary standpoints. Historians certainly engage in theoretical development; but it is rare that theory overtly dominates. Herein lies a strength. For sociologists, political scientists and others can, on occasion, drown in a welter of theory grounded on a slim empirical base. The historical approach is unique in its potential ability both to deal with and assess a range of primary source material bearing on the subject, to interweave that complex story with levels of theoretical explanation – and all within a framework which takes account of the passage of time. Historical cynicism as well as sensitivity to the assessment of competing sources and accounts must be accounted strengths. No historian would accept a single account or source at face value – a besetting sin in 'policy history' accounts emanating from non-historical sources. Historians as ideologically distant as Michael Howard and Christopher Hill are agreed that it is structure and process which are important in history.[31] We need, writes Hill, 'an understanding of history as a process, not just a bran-tub full of anecdotes'.[32] The generalising nature of history is central, as is its conceptual appreciation of change.

In researching contemporary history – of AIDS or any other area – that process is not without its difficulties. There is of necessity a reliance on oral sources. Contemporary history is particularly difficult for British historians for the lack of a Freedom of Information Act inhibits access to government departments under the thirty year rule. A journalistic 'contemporary history' such as Crewdson's analysis of Robert Gallo's laboratory notebooks would be impossible in the UK; the US legislation made access possible to National Institute of Health (NIH) data.[33] In fact, few of the historical accounts beginning to emerge have used conventional historical source material. Keith Alcorn's study of the genesis of the British government's mass media response to AIDS in 1987 is one of the few British accounts to use the minutes of the relevant committees.[34] Leaving aside these problems of sources, the writing and publishing of contemporary history has its own problems – not least where living 'historical actors' disagree with historians' interpretation of events. Nonetheless, AIDS has demonstrated important and in some senses unrealised potential in the historical approach to policy issues. The papers in this volume, mostly by historians, but with a sprinkling of policy scientists and an archivist, demonstrate some of the vitality of the contemporary history of AIDS and of its historical location in the social and health policy issues of the twentieth century and especially of the post-war period. The first part of the book concentrates on the 'larger agendas' into which AIDS fitted. Jeffrey Weeks in 'AIDS and the regulation of sexuality' locates reactions to AIDS in the history of sexuality and in particular the changing responses to sexual diversity in the post-war period. He draws attention to a complex matrix of reactions – liberalisation, but also moral confusion and a new conservatism emerging in the late 1970s and 1980s. AIDS emerged at a time when the political impetus of the UK gay movement had exhausted itself, but other strengths – a commercial subculture, self-help agencies – had emerged. This male community bound by ties of sex and of friendship was inevitably a vector for the rapid spread of the disease. But those friendship ties were also the bonds which made possible the spread of safer sex and community self-organisation. The nature of the policy response has also been complex in its relationship to the gay community. The government relied on that community to promote safe sex education while at the same time limiting sex education in schools and the promotion of homosexuality by local authorities. The same duality is apparent in the impact on the gay community, at one and the same time doubly stigmatised, yet also achieving new legitimacy and public acceptability.

AIDS fitted into that pre-history of gay politics and self-organisation; but it also fitted into other agendas. Jane Lewis in 'Public health doctors and AIDS as a public health issue' shows how AIDS' own initial definition as an 'epidemic disease' and subsequent redefinition as a chronic disease has mirrored the shift which public health doctors have been struggling to make since the late nineteenth century. They have attempted to redefine their role in a society no longer dominated by infectious disease. Public health, since the 'bacteriological revolution' of the late nineteenth century, has defined itself in terms of individual prevention, but has also seen its role very much in terms of the particular functions it has undertaken, for example hospital administration in the inter-war years. Public health, via the 1988 Acheson Report, has redefined its role again in the 1980s, this time in response to AIDS. But as Lewis argues, this 'new public health', although rooted in public health's past in theoretical terms at least, has not adopted that nineteenth-century determination to consider the social and environmental determinants of health, or to take issue with those in authority. What has continued is instead a focus on individual prevention; an intersectoral approach has failed to develop. The discipline continues to define itself around epidemiology as a means of scientific legitimacy.

AIDS has brought not just a revival of public health and the focus on epidemiology, but also revival of interest in 'testing' and surveillance. Bridget Towers in 'Politics and policy: historical perspectives on screening' shows in her analysis of past debates round 'sifting' and 'sorting', in case studies of radiography and TB; of testing for venereal diseases; of paternity testing; and the medical inspection of aliens, how the debates of the 1980s were mirrored in earlier discussions of screening. The epidemiological data thus produced tell us more about the social operation of the service provided rather than any model of scientific and technical progress or of objective 'knowing'. Towers also raises the continuing theme of confidentiality. This arose, she demonstrates from her case studies, not just out of the individually focused doctor–patient relationship but had wider bureaucratic ramifications in terms of the empowering of groups with access to information deemed to be confidential. Confidentiality can have managerial implications, and has historically been dependent on the status of the person concerned. In discussing the question of screening for commercial purposes (most notably by insurance companies), Towers comments how the practice has been legitimated by its definition as a medical activity. Yet insurance companies as much as state bureaucracies face real potential costs.

Ilana Löwy looks in 'Testing for a sexually transmissible disease 1907–1970: the history of the Wassermann reaction' at the 'pre-history' of testing from another perspective. Integrating perspectives derived from science, history and sociology, she demonstrates the emergence and establishment of the Wassermann test for syphilis between 1906 and 1940, a test which, unbeknown to its users at the time, brought with it a high rate of false positives and consequently artificially high diagnoses of syphilis. The development of specific 'treponemal tests' and the analysis of results of mass screening for syphilis brought a reassessment of its use and specificity. For AIDS, too, the problem of the high ratio of false positives in low risk populations and the social costs of such false positives have been important arguments in debates on mandatory or large-scale AIDS testing. Other uncertainties also surround the test; and, as Löwy comments, the history of the Wassermann reaction reminds us of the fragility of apparently uncontestable 'medical facts'.

Paul Weindling in 'The politics of international co-ordination to combat sexually transmitted diseases, 1900–1980s' traces the battleground of international health as illustrated by the particular example of sexually transmitted disease. In the inter-war years the League of Nations, the International Labour Office, Red Cross and the International Office of Public Health provided the organisational bases for the complex interaction of pro-natalism and social purity movements; of feminists and pacifists. Medical science was an important legitimating source of expertise; and the League of Nations concentrated on a restricted range of scientific issues – the Wassermann test, salvarsan – and on technical input in terms of medical education. The World Health Organisation model as it developed post-1948 was a medical one and the introduction of antibiotics strengthened this tendency. Weindling points to how scientism, militarism and state controls have dominated international initiatives. The powers and responsibilities of international organisations remain unresolved, between a minimalist role as agencies of epidemiological intelligence and a universalist drive to formulate optimum standards transcending the interests of ruling elites in nation states.

Weindling's call for a blending of medical priorities with humanitarian values is echoed by William Muraskin in 'Hepatitis B as a model (and anti-model) for AIDS'. Muraskin sees a very clear historical lesson in the case of hepatitis B, a disease with some clear similarities – and differences – with AIDS. The scientific lessons were learnt from hepatitis B, argues Muraskin, but the social lessons were not. Hepatitis B remained a low profile disease and the problem of carriers of the disease was not dealt with, largely, in this interpretation, because carrier status affected health care workers. Concern about Asian immigrants and hepatitis B and about schoolchildren carriers were perceived as problems of discrimination. Muraskin castigates the policy decision to put the protection of the rights of carriers above the rights of the uninfected population. The result was a failure to generate solutions, such as safe sex, needed subsequently during the AIDS epidemic.

Although it deals with the 'pre-history' of AIDS, Muraskin's is a paper which draws a direct policy lesson. The second part of the book moves to the theme of AIDS itself as history – the 'contemporary history' of the past decade. Virginia Berridge in 'AIDS and British drug policy: continuity or change?' surveys the apparent changes which AIDS has brought in British drug policy. Many commentators have focused on the change to a health-based rather than a penal approach via the concept of harm-minimisation and the incorporation of drug policy within a public health paradigm. Berridge, while acknowledging the immediate reality of change, locates the shifts which have taken place within the context of tensions and concepts legitimised in drug policy since the late 1970s. Harm-minimisation was already the objective of a revisionist drug 'policy community'; AIDS gave the concept political acceptability. Berridge analyses current policy in the light of some continuing themes in drug policy; of medical legitimacy; the relationship between technological and policy change; and the long-term history of harm-minimisation as a guiding theme in British policy.

Warwick Anderson in 'The New York needle trial: the politics of public health in the age of AIDS' tells the very different story of US drug policy and in particular of the history of the attempt to establish controversial policy change in New York City. The attempt to secure the acceptability of needle exchange in New York was to be legitimised by a technical scientific procedure, that of the clinical trial. In Britain the apparent scientific neutrality of research – via the epidemiological assessment conducted by the Monitoring Research Group – did help secure controversial policy change. But the local limitations in New York on the role of expert groups meant that science did not have this autonomous authority. Anderson's aim is not to draw a 'lesson of history' from this; his paper does not discuss what might or should have been.

Victoria A. Harden and Dennis Rodrigues in 'Context for a new disease: aspects of biomedical policy in the United States before AIDS' also focus on US politics round AIDS, in this case the response of the federal research organisations to AIDS. The authors use two case studies against which to contextualise that response. These are the establishment of the structure of the NIH system for distributing grants, and the emergence of targeted disease programmes and planning. The new concept of planning for research (a process which had its parallel in the UK with the Rothschild 'customer–contractor' changes) and of targeting specific diseases is illustrated via the politics of the response to DNA and to Legionnaires' disease. As Harden and Rodrigues note, the quick NIH response in that latter case may have heightened optimism around AIDS. But the research planning process proved useless in response to this new disease. Using internal documents, the authors survey the initial NIH reaction to AIDS and compare the changes required to those needed laboriously to re-direct a large ship already set on a particular course. They stress the importance of the mid-1982 move from an 'environmental agent' model to an infectious pathogen, and relate the stages of reaction to Charles Rosenberg's three-stage model of an epidemic.

Ewan Ferlie in 'The NHS responds to HIV/AIDS' has also had access to internal policy documentation. But his paper deals with the local dimension of policy making in British District Health Authorities. Ferlie, trained as an historian, writes from within a business school and from an organisation theory perspective. Many of the concepts are shared with historical ones, in particular the problem of organisational change over time, and the particular role of crisis in stimulating innovation. Here there is an organisation theory literature as well as an historical one. Ferlie delineates a cycle from innovation to institutionalisation which is also underlined by 'historical' work on AIDS. Managers, seen as key figures in National Health Service (NHS) policy at the local level in the 1980s, he finds 'dull' in relation to AIDS. Far more important were the clinical 'product champions', and the politics of the particular District were crucial where funding was concerned.

Ferlie's analysis of the District Health Authorities' response found new agendas being defined and a second generation of 'product champions' emerging as part of the move towards institutionalisation. John Street, in 'A fall in interest? British AIDS policy, 1986–1990' also deals with this later stage of AIDS, this time from a policy science perspective. Using the theme of 'crisis to complacency' as the normal pattern of response to pressing social policy issues, he uses AIDS as a case study to see if this model is indeed appropriate. Street scrutinises the issues raised by the 1987 Report of the Social Services Committee Enquiry into AIDS to see what has happened in the intervening years. He also examines the particular role of politicians and in particular of Mrs Thatcher as Prime Minister. The role of the All Party Parliamentary Group on AIDS is seen as important in maintaining consensus. The arrival of reform of the NHS on the political agenda also served to deflect attention from AIDS. Street concludes that the crisis–complacency model is too simplistic. Quite significant changes and developments in policy can take place without the overt intervention of political or media interest. This has been the case for AIDS policy development since 1987. Nonetheless, the role of politicians cannot simply be discounted.

Politics has played a key role in French policy making, according to Monika Steffen's analysis in 'AIDS policies in France'. Steffen, like Street, a policy scientist, views AIDS in France within a perspective of change over time. Steffen locates the liberal reaction to AIDS in France in pre-existing traditions of politics of health service organisation and public policy formation. The reaction to AIDS fitted into the pre-existing norms of social policy over the preceding three decades. But a large-scale policy 'push' was delayed in France until the late 1980s, despite the existence of larger relative numbers of AIDS cases in France than in other western European countries. Steffen locates this delay in the initial absence of scientific consensus around AIDS and, crucially, in the delayed emergence of political consensus. Split political control between a liberal Prime Minister and a socialist President and the emergence of a strong National Front movement made AIDS more of a potentially politically contentious issue than in Britain. The response, when it came, was ultimately one which protected individual liberty; and, as in Britain and the US, gave legitimacy to gay and other non-medical groups.

Finally, Janet Foster presents in 'AIDS: the archive potential' the work of the pilot survey of AIDS archives carried out through the AIDS Social History Programme. This unique study set out not to collect archival material, but to indicate how much material there was and the problems involved in its preservation. This was an exercise in raising archival consciousness, but also in defining key problem areas. The archives of voluntary sector organisations with a national role appear she concludes to be especially at risk.

No volume on contemporary history, let alone on AIDS, can claim to be comprehensive. There are areas of pre-history and of AIDS as history where, as yet, little has been researched or written. Nevertheless, the papers in this collection demonstrate both the vitality of the more recent historical approaches to AIDS and the cross-fertilisation with the perspectives of other disciplines which is possible. They will, it is hoped, encourage further analysis of the social and health policy issues of the post-war period.

NOTES

1 Among the earlier examples were the 1986 issue of the Millbank Quarterly, subsequently republished as E. Fee and D. M. Fox (eds.), *AIDS: The Burdens of History* (Berkeley, 1988); 'In time of plague', *Social Research*, 55, 3 (1988); A. M. Brandt, *No Magic Bullet. A Social History of V.D. in the U.S. since 1880* (Oxford, 1985), was republished in 1987 with a new chapter on AIDS. British examples

include F. Mort, *Dangerous Sexualities: Medico-Moral Politics in England since 1830* (London, 1988); R. Davenport-Hines, *Sex, Death and Punishment* (London, 1990).

2 A. Brandt, 'AIDS in historical perspective: four lessons from the history of sexually transmitted diseases', *American Journal of Public Health*, 78 (1988), 367–71.

3 R. Porter, 'History says no to the policeman's response to AIDS', *British Medical Journal*, 293 (1986), 1589–90. See also R. Porter, 'Plague and Panic', *New Society*, 12 December 1986, 11–13.

4 M. W. Adler, 'History of the development of a service for the venereal diseases', *Journal of the Royal Society of Medicine*, 75 (1982), 124–8. M. W. Adler, 'The terrible peril: a historical perspective on the venereal diseases', *British Medical Journal*, 281 (1980), 206–11. See also J. Austoker, 'AIDS and homosexuality in Britain: an historical perspective', in M. W. Adler (ed.), *Diseases in the Homosexual Male* (London, 1987).

5 Chief Medical Officer, *On the State of the Public Health. The Annual Report of the Chief Medical Officer of the DHSS for the Year 1986* (London, 1987).

6 House of Commons, Social Services Committee, *Third Report. Problems Associated with AIDS Volume 1*, Session 1986–8 (London, 1987), vii.

7 See V. Berridge and P. Strong, 'AIDS policies in the UK: a study in contemporary history', *Twentieth Century British History*, 2, 2 (1991), 150–74.

8 For some discussion of the concept, see D. M. Fox, 'Chronic disease and disadvantage: the new politics of HIV infection', *Journal of Health Politics, Policy and the Law*, 15 (1990), 341–55.

9 C. Rosenberg, 'What is an epidemic? AIDS in historical perspective', in S. R. Graubard (ed.), *Living with AIDS* (Cambridge, Mass., and London, 1990), republishing spring and summer 1989 issues of *Daedalus*, 118, 2 and 3.

10 Fee and Fox, 'Introduction: AIDS, public policy and historical inquiry', in Fee and Fox (eds.), *AIDS: The Burdens of History.*

11 D. Parker, 'History as bunk', *Times Higher Education Supplement*, 1 June 1990, 14.

12 As one example of the historiography of radical history, see R. Samuel (ed.), *History Workshop 1967–1991. A Souvenir and Collectanea* (Oxford, 1991). A survey of the vitality of the right and some possibilities for a response is given in P. Curry, 'Thompson, Clark and beyond: the future of English Marxist social history' (unpublished paper). See also Juliet Gardiner (ed.), *The History Debate* (London, 1990).

13 P. Thane, 'Introduction', in P. Thane (ed.), *The Origins of British Social Policy* (London, 1978).

14 E. Fee and D. M. Fox, 'The contemporary historiography of AIDS', *Journal of Social History*, 23 (1989), 303–14.

15 G. Herdt and S. Lindenbaum (eds.), *The Time of AIDS. Social Analysis Theory and Method* (Newbury Park, Ca., 1992).

16 D. Altman, *AIDS and the New Puritanism* (London, 1988).

17 G. Oppenheimer, 'In the eye of the storm: the epidemiological construction of AIDS', in Fee and Fox (eds.), *AIDS: The Burdens of History.*

18 D. M. Fox, P. Day and R. Klein, 'The power of professionalism: AIDS in Britain, Sweden and the United States', *Daedalus*, 118 (1989), 92–112.

19 Z. Schramm-Evans, 'Responses to AIDS, 1986–1987', in P. Aggleton, P. Davies and G. Hart (eds.), *AIDS: Individual, Cultural and Policy Dimensions* (London, 1990); H. Edgar and D. J. Rothman, 'New rules for new drugs: the challenge of AIDS to the regulatory process', in D. Nelkin, D. P. Willis and S. V. Parris (eds.), *A Disease of Society: Cultural and Institutional Responses to AIDS* (Cambridge, 1991).

20 Nelkin, Willis and Parris (eds.), *A Disease of Society.*

21 J. Elford, R. Bor, L. Sherr and G. Hart, 'AIDS – ten years on', *AIDS Care*, 3 (1991), 235–8.

22 Prof. Tony Coxon, introducing a conference on HIV/AIDS: Research and Policy at the King's Fund, 3 May 1991.

23 R. Porter, 'Epidemic of Fear', *New Society*, 4 March 1988, 24–5, reviewing R. Shilts, *And the Band Played On: Politics, People and the AIDS Epidemic* (London, 1988).

24 For example in Britain, R. McKie, *Panic: The Story of AIDS* (Wellingborough, 1986).

25 M. D. Grmek, *History of AIDS. Emergence and Origin of a Modern Pandemic*, trans. R. C. Maulitz and J. Duffin (Princeton, 1990).

26 For the entwining of anthropological and historical perspectives, see Herdt and Lindenbaum (eds.), *The Time of AIDS.*

27 P. Aggleton and H. Homans (eds.), *Social Aspects of AIDS* (London, 1988); P. Aggleton, G. Hart and P. Davies (eds.), *AIDS: Social Representations, Social Practices* (London, 1989); Aggleton, Davies and Hart (eds.), *AIDS: Individual, Cultural and Policy Dimensions*; P. Aggleton, G. Hart and P. Davies (eds.), *AIDS: Responses, Interventions and Care* (London, 1991).

28 See, for example, the entries for the Aled Richards Trust and for Simon Watney in J. Foster, *AIDS Archives in the UK* (London, 1990).

29 See, for example, the outcry in the *Guardian* in 1991 in response to an article by R. Haselden, 'Gay abandon', *Weekend Guardian*, 7–8 September 1991, 20–1, which had suggested that not all gay men had adopted safe sex practices.

30 The author presenting an earlier version of this work to a seminar of policy scientists at the King's Fund was confronted by complete disbelief. Brendan Dunleavy in 'The study of public policy: do historians have a role?' (paper presented at the Institute of Historical Research May 1990) has also argued against the role of history. By contrast, P. N. Stearns, 'History and public policy', in G. J. McCall and G. H. Weber, *The Roles of Academic Disciplines in Policy Analysis* (London, 1984), demonstrates some strengths of the 'policy relevant' historical approach.

31 M. Howard, *The Lessons of History* (Oxford, 1991).

32 C. Hill, 'History and the Present', 65th Conway Memorial Lecture 1989.

33 J. Crewdson, 'Science under the microscope', *Chicago Tribune*, 19 November 1989.

34 K. Alcorn, 'AIDS in the public sphere', in E. Carter and S. Watney (eds.), *Taking Liberties: AIDS and Cultural Politics* (London, 1989).

I

The pre-history of AIDS

1

AIDS and the regulation of sexuality

JEFFREY WEEKS

Introduction

The HIV/AIDS epidemic is framed, if not burdened, by many histories. There are histories of past epidemics and diseases, including sexually transmitted diseases; histories of scientific investigation, and of medicine and social hygiene; histories of the various groups affected by HIV and AIDS: of homosexuals, of drug users, of the poor and racially disadvantaged in the urban centres of western nations, and of the poor and exploited in the developing world; and there are histories of social policy and of welfare policies, or of their absence, which can help us to understand the various phases of the political and governmental response to HIV and AIDS. AIDS is already a deeply historicised phenomenon.[1]

But at the centre of any attempt to understand the response to the epidemic in the west must be the history (or rather histories) of sexuality. At the most basic level this is because sexual intercourse is one of the most efficient means of transmission of the virus, and changing patterns of sexual interaction help explain its rapid spread from the late 1970s. There is, however, a more profound reason why we need to situate HIV and AIDS in a history of sexuality. AIDS was identified at a particular moment in that history, when values and behaviour were in a period of unprecedented flux, and when sex-related issues came close to the top of the political agenda.

The syndrome was first identified in a highly sexualised community, the gay community, which was the focus of heated controversy as well as (or perhaps because of) an unparalleled growth and public presence. It was also a period when to an extraordinary degree sexuality had become a major element in political debate and mobilisation. Not surprisingly, therefore, AIDS became for many a potent symbol for all that had changed, or threatened to change. Change was not, of course, confined to sexuality, but changes in sexual behaviour seemed to condense all the other changes (in personal behaviour, in the changing demographic make-up of western populations, in forms of social regulation and in the changing relationship between First and Third Worlds) that were transforming western, and world, culture by the early 1980s. The AIDS crisis emerged at a crucial moment of cultural uncertainty, particularly with regard to sexuality, and the initial reaction to the epidemic, as well as the subsequent response at all levels, from popular fear and panic to national and international intervention, has been indelibly shaped by that fact.[2]

This paper, therefore, explores the responses to HIV and AIDS through an exploration of our current sexual preoccupations. I begin with an account of key tendencies in what I shall call the 'new history of sexuality', which can contribute to our understanding of the impact of the epidemic. Then I trace in more detail the changing patterns of the social organisation and regulation of sexuality in Britain which helped shape the initial, and continuing, reaction to the crisis. Attitudes towards homosexuality were central to the debates over the appropriate forms of regulation. The gay community in turn bore the brunt of the early 'moral panic' (a contested but to my mind still valuable concept, to which I shall return) and which at the end of the first decade of the crisis still faced the main burden of the epidemic. Responses to homosexuality, then, are necessarily central to the discussion. Finally, I attempt an assessment of the complexity of social responses to HIV and AIDS (both as a syndrome of diseases, and as a symbolic presence) in our deeply historicised present.

AIDS and the new history of sexuality

Since the 1960s there has been a revolution in the historical understanding of sexuality. From being (like gender) scarcely a spectral presence in social history, sexuality has increasingly been seen as a key element for understanding the social dynamics of modern society. At the centre of the new history is a recognition that sexuality is far from being the purely 'natural' phenomenon which earlier historians took for granted, and which largely shaped their avoidance of the subject. If sexuality is a constant, why bother to study it?

We now see, on the contrary, that far from being outside of history, 'sexuality', as the social organisation of sexual relations, is a product of many histories, from the *longue durée* of population changes and shifts in the economic and social structure of modern society, to the shorter term interventions of religious leaders, 'moral entrepreneurs', legislators and sexual activists and minorities. 'Sexuality' in an inadequate but now familiar, if controversial, term is 'socially constructed'.[3]

We can draw from this now substantial body of work three major themes which are central to any attempt to understand the impact of AIDS: the symbolic centrality of sexuality in modern society; the historical nature of sexual, like other social, identities; and the complexity of regimes of sexual regulation. Before deploying these themes for a more detailed analysis, I want to indicate briefly the general ways in which they can illuminate the crisis around HIV and AIDS.

First of all, let us take the symbolic centrality of sexuality. Sexuality has been at the heart of social discourse for a very long time. The regulation of sexual behaviour was central to the institutionalisation of Christianity, and hence to the formation of what we know as European civilisation. Within the period we now think of as 'modernity', since roughly the eighteenth century, sexual behaviour has been a besetting preoccupation in all the crises and initiatives of industrialisation and 'modernisation'. This is because sexuality, far from being the most natural thing about us, is in many ways the most socialised, the most susceptible to social organisation. To put it another way, the terrain of sexuality is like a conductor of currents, whose origins lie elsewhere, but whose battleground is sexual belief and behaviour. Sexuality, as Michel Foucault put it, has been assigned so great a significance in our culture because it has become the point of entry both to the lives of individuals and the life, well-being and welfare of the population as a whole. But it is also, of course, the focus of fantasy, individual and social, and of judgements about what is right or wrong, moral or immoral.[4]

It is not surprising, then, that the emergence of a sex-related disease, or set of diseases, in the early 1980s became the focus of social anxieties, fears and panics, just as the syphilis epidemic produced significant social, and symbolic, effects in the nineteenth century.[5] The origins of the sense of uncertainty, amounting in many people's minds to a generalised crisis of western culture, may have been complex and diverse, but the emergence of AIDS provided a convenient focus, a symbolic site, for articulating the new social imagery.

The question of identity was central to what for the sake of convenience I am calling a crisis around sexuality. Here the work of the new history has been perhaps most original and innovatory. What it has sought to demonstrate is that the socio-sexual identities (such as 'heterosexual' or 'homosexual') that we now take for granted as so natural and inevitable are in fact historical constructs, and fairly recent constructs at that.[6] To be more specific, since at least the nineteenth century, and possibly earlier – the debate is still open – western culture has become increasingly concerned with identifying what you do with what you are, with establishing object choice as the key to our sexual natures. In a phrase, heterosexuality and homosexuality may always have existed (if we take those terms to apply to general sexual activity), but 'homosexuals' and 'heterosexuals' have not.

The historicisation of sexual identities helps us to understand some of the most important features of the initial reaction to the AIDS epidemic. The existence of the 'homosexual' as a generally execrated category, the description of a particular type of person, the 'other' whose very presence served to define what is normal in the rest of the population, was central to the early definition of AIDS as a homosexual disease, the 'gay plague'. If homosexuality is the exclusive characteristic of the 'deviant', then necessarily the disease must have something to do with the lifestyle of homosexuals. From this stemmed the disastrous reluctance of many early scientists to come to terms with heterosexual transmission, and the dimensions of the heterosexual epidemic, especially in Africa.

This brings us to the third lesson we can draw from the new history, concerning the complex patterns of regulating sexuality. Two key elements stand out: the formal regulation of sexual behaviour through church and state; and the less formal, but frequently closely connected, forms of regulation of sexuality through the discourses of medicine, sexology, 'public health' and social hygiene. The important point here is that these are rarely articulated together in a neat fit; more often than not they are in contradiction with one another, and often are torn by self-contradictions. Different agents of the state (the bureaucracy and the political leadership, central and local bodies) take different views, have different priorities and strategies. Churches have their own moral agenda, and intervene with variable force and effect. The medical establishment might promote a health policy which is sharply at odds with political priorities. All these tensions were manifest in the response to the new health crisis.

At the same time, a deep historical awareness of the shaping roles of the state, religion, science and medicine in sustaining a model of homosexuality as deviant and 'other' helped to determine the early reaction of people with AIDS, and gay activists, to the epidemic. There was a deep-rooted fear that having only recently escaped from the opprobrious definitions of homosexuality (male homosexuals had only recently been partially decriminalised, the 'medical model' of homosexuality was still prevalent) AIDS could easily lead to the re-medicalisation, and possibly re-criminalisation, of homosexuality.[7]

All these factors suggest the complex ways in which sexuality is socially organised. Our sense of ourselves, and our place in the world, is shaped at the intersection of a series of often conflicting discourses: religious, legal, medical, educational, psychological, sexological, communal, and so on. Our subjectivities and identities are negotiated through the network of meanings and potentialities these offer. They entangle us, shaping our sense of what we are, and can become. But the very complexity of meanings that exist in the contemporary world suggests that we are not trapped within them; on the contrary, they provide the space for constant re-negotiations and re-definitions.

The period since the 1960s has seen rapid changes in social and cultural life,[8] and a closely related proliferation of new discourses around sexuality, re-shaping and re-ordering the possibilities for living our sexual lives. AIDS appeared in the midst of a cacophony of debate, experimentation and consequent reaction concerning sexuality. Responses to it were, not surprisingly, complex. In turn, the epidemic has initiated new discourses (for example, concerning 'safer sex', health, and social regulation) which are likely to shape powerfully the ways in which we think and live sexuality for the foreseeable future. The response to AIDS casts a strong searchlight on the sexual preoccupations of our time. It also throws a long shadow on what is to come.

The regulation of sexuality

The key to understanding the impact of the AIDS crisis lies in recognising that it emerged in the midst of what can best be described as an 'unfinished revolution' in attitudes towards, and in the regulation of, sexuality, and especially homosexuality. On the one hand there has been a striking double-shift in attitudes over the past generation. This has involved both a liberalisation of attitudes towards issues such as marriage and divorce, pre-marital sex, birth control and abortion, and towards homosexuality; and an apparent secularisation of belief systems, with the decline of traditional, usually Christian-based, absolutist standards, and the emergence of more pragmatic belief systems. The development from the early 1970s of a vigorously open and diverse lesbian and gay community is one index of the change, though far from being the only one.[9]

But these shifts have been accompanied by a high degree of moral confusion (where attitudes and beliefs have frequently lagged behind behavioural changes). Uncertainty and confusion, in turn, provided the elements for a moral mobilisation around sexual issues, which has given sexuality a new political salience. This is most dramatically illustrated by the emergence since the 1970s of a new conservatism, often allied – though less so in Britain than elsewhere – to fundamentalist religion, which has focused a great deal of energy on key moral issues: abortion, above all, especially in the USA, but also such themes as sex education and, most obviously in relation to AIDS, the claims of lesbian and gay politics. AIDS emerged as a focus of social concern at precisely the moment in the early 1980s when these new political forces were attempting to achieve a new cultural hegemony in North America and Britain especially.[10]

One way into the understanding of the complex forces at work is through the shifting patterns in the regulation of sexuality during this period. The late 1960s had witnessed the most striking changes in the legal framework of sexuality for almost a hundred years. Between 1967 and 1970 there was significant new legislation on abortion, homosexuality, stage censorship and divorce. Together with earlier changes (such as changes to the laws on obscene publications) these constituted what became known as 'permissiveness'.[11]

Behind the legal changes was a collapse of a whole pattern of regulating sexuality, enshrined in the assumption that the law had a right and a duty to state what was right and wrong in both public and private life. In place of a legal absolutism that was widely perceived as being incapable of responding appropriately to a more open and pluralistic culture, a new strategy of regulation emerged, most clearly articulated in one of the key statements of the period, the 'Wolfenden Report' of 1957.[12]

The report, and the raft of legislation that attempted to enact its implications, based its proposals on a clear distinction: between private morality and public decency. The role of the state, it declared, was not to impose a particular pattern of private morals; that was the role of the churches and of individual conscience. The law's role was to uphold acceptable standards of public order and decency.

The legislation of the 1960s was cautious and modest in the actual changes it sought to make. So, for example, the Abortion Act of 1967 did not allow abortion on demand; there was no divorce by consent; and, most significantly, homosexuality was not fully legalised, nor was it in any real sense legitimised. There was no attempt to create new rights, or positively to assert the values of different sexual lifestyles. The declared aim, rather, was to find a more effective way of regulating sexual behaviour than the draconian (and largely ineffective) methods of the old laws had allowed.[13]

So the Wolfenden strategy did not herald any espousal of 'sexual liberation'; its philosophy was well in the tradition of English liberalism, and its policy implications were modest and pragmatic. That was not, however, how it was seen by many, either at the time, or subsequently. For the upholders of legal absolutism and for the morally conservative the approach represented an abandonment of moral standards in favour of moral relativism. During the subsequent decades the legislative revolution of the 1960s became for many the symbol of all that had gone wrong in 'the sixties', the decade of supposed sexual liberation and moral collapse. As the conservative commentator, Ronald Butt, put it, 'In some matters, a charter of individual rights was granted which unleashed an unprecedented attack on old commonly held standards of personal behaviour and responsibility.'[14]

But for some of the radical forces that emerged from the late 1960s, around feminism and gay liberation, the reforms were a symbol also, but this time of a failed liberalism, too little, too late. The British gay movement that emerged in 1970 grew in the space that law reform had helped shape. The new generation of lesbian and gay activists acted *as if* they had been given new rights by law reform. But the spirit of the new radicalism was distinctly different from that of the Wolfenden strategy. By advocating 'coming out', that is declaring one's gayness, it sought to dissolve the privacy of sexual taste, to make sexuality a public issue. Through its militancy and the carnivalesque way in which it demonstrated its new sense of collective consciousness it attempted to break the taboos about public displays of homosexual love and affection.[15]

In other words, the Wolfenden approach, with its rationalistic assumptions about an acceptable distinction between public and private spheres, satisfied neither of the polarised sexual political forces that emerged vocally in the 1970s. For the radicals, it had not gone far enough; for the right, which was becoming politically dominant, especially after the election of the Thatcher government in 1979, it had gone too far. By the end of the 1970s and the beginning of the 1980s, there were clear signs that the Wolfenden strategy itself was losing its purchase on debate, as the political climate shifted.[16]

Behind this was a wider political and cultural crisis, for which the emergence of what Stuart Hall has called the 'authoritarian populism' of the Thatcher governments offered an apparent solution (at least, perhaps, to that section of the British electorate which voted for the Thatcher-led Conservative Party in 1979, 1983 and 1987).[17] Crucially, alongside its commitments to 'a strong state and a free economy' was a moral project, summed up polemically in Mrs Thatcher's potent espousal of a return to 'Victorian values'.[18]

It is important to recognise that this moral project was never during the 1980s pursued with the same enthusiasm as the economic revolution close to Mrs Thatcher's heart, and the impact of Thatcherism on moral attitudes, and even sexual regulation, was in the end limited.[19] Nevertheless, it is relevant to the understanding of the initial impact of, and response to, AIDS that such a forceful exponent of opposition to 'the sexual revolution' was in power in Britain during the early years of the AIDS epidemic. This was a decade when political issues were persistently moralised, and moral issues were ever in danger of becoming political issues, and that profoundly defined the parameters of the response to AIDS. Not least, AIDS raised difficult questions about the relationship between private behaviour and public policy in the most sensitive and controversial area of all, that of sexual behaviour.

The stress on family values, though somewhat erratically pursued, as some of Mrs Thatcher's ideological friends frequently complained, was perhaps the major moral response to 'permissiveness' during the period. Its inevitable accompaniment was a challenge to those who had most fervently sought to undermine the hegemony of the family, and of these homosexuality represented the most potent symbol.

Homosexuality, particularly as represented by the militancy of lesbian and gay politics, represented, in Anna Marie Smith's powerful term, an overflowing of 'radical difference', a challenge to the normality and inevitability of orthodox family life.[20] This not only threatened (at least in New Right discourse, if not elsewhere) the hierarchy of difference between men and women, adults and children represented by the traditional model of the family, but also made public what was best confined to the decency of the private sphere.

It was an historic accident that HIV disease first manifested itself in the gay populations of the east and west coasts of the United States, and subsequently in similar populations throughout the west. But that chance shaped, and has continued to form, the social and cultural response to AIDS. Originally officially designated by its association with the gay community ('gay cancer', GRID or Gay Related Immune Deficiency), and easily encapsulated in tabloid headlines as the 'gay plague', HIV and AIDS were immediately classified as the diseases of the diseased, caused by, and revealing, the problems inherent in a particular way of life: 'promiscuity', 'fast-lane' lifestyles, irresponsibility, and all the other terms deployed against what by the early 1980s was being identified as a clamant, but unpopular, minority.[21]

The lesbian and gay community in Britain never achieved the public presence or sophistication of the American, nor therefore the notoriety. It had grown significantly during the 1970s, largely through the stimulus of the radical gay liberation movement which was launched in 1970, in large part under American influence. During the subsequent decade the movement had developed rapidly, absorbing and transforming the older, more reformist, homophile groupings, and in turn stimulating an unprecedented growth of homosexual organisations, social facilities, publications, and a new self-confidence and sense of identity amongst lesbians and gay men.[22]

But by the early 1980s the initial political impetus had exhausted itself. The gay liberation movement itself had fragmented in the early 1970s, and the various militant groupings it had given rise to were themselves in crisis by the early 1980s. Even *Gay News*, which had been central to the identification and articulation of a sense of common experience in the 1970s, entered a terminal crisis in the early 1980s, and had effectively disappeared by 1983.[23] There was a felt mood of vulnerability in the British gay community as policies swung dramatically to the right under Margaret Thatcher. The close ties with the American gay scene, stimulated by a greater ease of transatlantic travel, fed the sense of apprehension. The various anti-gay campaigns of the late 1970s in the USA, most famously the crusade of Anita Bryant to save America from sodomy,[24] had been carefully watched in the UK, and there was a strong belief amongst many activists that the same would follow in Britain.

Yet this sense of vulnerability, and fear of a backlash against the gains of the 1970s, must not lead us to ignore the real strengths of the lesbian and gay communities by the early 1980s. There was a burgeoning commercial subculture, for men at least, which constantly expanded the possibilities for social and sexual interaction. The demise of broad-based campaigning organisations did not mean that a lesbian and gay politics had disappeared. On the contrary, the subsequent decade, in part despite, in part because of, AIDS, saw a new political energy: of lesbians active in the women's movement; of openly lesbian and gay activists in the major political parties, especially the Labour Party; the emergence of distinctive campaigns for lesbian and gay rights in various local government areas, especially in London, Manchester and other major cities; and a continued development of gay-related information and support services, such as London Gay Switchboard (subsequently Lesbian and Gay Switchboard), with similar organisations throughout the country. Moreover, the example of the gay movement stimulated a proliferation of alternative radical sexual identities, around paedophilia, sado-masochism, transvestism and the like, giving rise to what became known as a radical 'sexual fringe'.[25]

Of course, there was a paradox inherent in this expansion. The ties of community, at least amongst gay men, facilitated the rapid spread of HIV in the gay community. Sex, and a greater freedom in the pursuit of sexual freedom and choice, was a bond that bound the male community together, but that inevitably provided a vector for the rapid spread of disease. On the other hand, the bonds constructed and reaffirmed through a new ease with sexuality also made possible the emergence of a new discourse of 'safer sex', and provided the nexus of friendships and personal ties that was to be a vital factor in the community response to the developing health crisis.[26]

Inevitably, it was the sexuality of the male gay community, and the radical alternative it implied to the traditional values, 'the old virtues of discipline and self-restraint' endorsed by Mrs Thatcher,[27] which became the focus of the early fears aroused by AIDS. But beyond this, as I have already tried to indicate, were a wider set of fears about cultural change that the links between the gay revolution and HIV disease came to symbolise. At the heart of these fears, I would argue, was the challenge posed by diversity.

AIDS, as a syndrome of diseases that preeminently during the 1980s affected marginal and marginalised people – male homosexuals, drug users, the poor and black people of American cities, men and women of the Third World – became a symbol of diversity, of the problems posed by cultural and sexual change. AIDS was both global in its impact and implications, and local in its manifestations and effects. It could be represented as the harbinger of that 'sense of an ending' which was at the centre of the new cultural conservatism. It unsettled the enlightenment faith in the triumph of science, and reason. But it also demanded new resources at a time when conservative governments throughout the west were intent on reducing the role of public provision. And it required an empathetic understanding of the implications of cultural pluralism in a climate which was rife with the quest for new absolutes.[28] AIDS, as Nelkin *et al.* have argued, 'demonstrates how much we as a "culture" struggle and negotiate about appropriate processes to deal with social change, especially in its radical forms'.[29]

The unprecedented nature of the problems posed by the disease as it spread in Britain in the 1980s, combined with the peculiarly uncertain response evoked by the needs of the gay community, helped determine the contours of the immediate response to the crisis. This has been widely characterised as one of 'moral panic', though this description has also been sharply criticised.[30]

The setting of limits, the drawing of boundaries, is precisely one of the functions of the classic elements of 'moral panics', and we can, I believe, still use this concept, with caution, as a helpful heuristic device to explore the deeper currents which shaped the developing HIV/AIDS crisis. The concept was developed to describe the response to the problem of youth in the 1960s, and has been used in a variety of contexts since. Classically, moral panics focus on a condition, person or group of persons who become defined as a threat to accepted social values and assumptions. They tend to develop in situations of confusion and ambiguity, in periods when the boundaries between what are seen as acceptable and unacceptable behaviour become blurred, and need redefinition. Over the past generation there have been an apparently endless series of such panics, many of them around moral and sexual issues: areas, clearly, where boundaries are uncertain, where anxieties about the parameters of legitimate behaviour are most acute. They reveal above all an uncertainty about sexual beliefs, which made it possible to mobilise anxieties and promote symbolic solutions.

In the case of AIDS we can detect several key features. There was, first of all, the characteristic stereotyping of the main actors as peculiar types of monster, leading in turn to an escalating level of fear and perceived threat. The response to the perceived threat from the tabloid press was particularly important here between 1983 and 1986, in shaping the image of the 'gay plague'.[31] This in turn led to the 'manning of the barricades' by the moral entrepreneurs, and the seeking out of largely symbolic solutions: quarantine, compulsory blood testing, immigration controls.[32] More widely there were manifestations of what Susan Sontag has called 'practices of decontamination',[33] against lesbians who at this stage did not seem vulnerable to HIV, as well as gay men who were: restaurants refused to serve gay customers, gay waiters were sacked, dentists refused to examine the teeth of homosexuals, technicians refused to test blood of people suspected of having AIDS, paramedics fumigated their ambulances, hospitals adopted barrier nursing, rubbish collectors wore masks while collecting garbage, prison officers refused to move prisoners, backstage staff in theatres refused to work with gay actors, distinguished pathologists refused to examine bodies, and undertakers refused to bury them.[34]

These were not universal experiences; there was altruism, self-sacrifice and empathy as well. But all these things happened, to people vulnerable to a devastating and life-threatening disease; and the vast majority of these people were homosexual. It is difficult to avoid seeing such manifestations as anything but panic-driven. The real plague as the *Guardian* famously put it, was panic.[35]

Of course, AIDS-related illnesses in the early 1980s were mysterious; fear was legitimate. It was not simply dreamt up by the press. There was a general sense of uncertainty, which shaped the early responses of the medical profession as well as politicians. Moreover, to describe these happenings as simply manifestations of a moral panic does not do justice to the complexity of what was happening, nor to the prolonged nature of some of the responses. It is perhaps better to see what happened as a series of panics, occasioned by particular events or new information or rumours, unified through a continuing discourse of hostility towards homosexuality (and the pursuit of circulation). Moral panic theory, moreover, does not explain why these social flurries of anxiety occur: they simply draw our attention to certain recurring phenomena, providing a template for description rather than a full analysis. Explanations of the AIDS panic must be found in all the other factors we have discussed.

Nevertheless, with all these qualifications, there is still some merit in using the term 'moral panic' as a way of describing the first major public stage of the response to AIDS, between roughly 1983 and 1986, not least because a perception of how the public was reacting determined the responses both of the community most affected, and of the government.

The complexity of social responses

My argument is that initial reactions to AIDS were structured by a complex history, which in turn produced a complex set of responses. To illustrate this I want, first of all, to look again at the experiences of the gay community. Identities in the contemporary world, it may be argued, are the means by which we negotiate the hazards of everyday life, and assert our sense of belonging.[36] They are rooted in history, or at least 'History' is evoked, but their effectiveness depends on their strategic placing in a complex play of power relations. The response to the new health crisis from the gay community provides a classic example of this. In particular, the early voluntary response to AIDS was able to draw on the sense of a common identity that had developed in the 1970s in order to operate in a situation where national government responses were absent, and where hostility towards the community was increasing. The Terrence Higgins Trust, which emerged in 1983 as the first British voluntary grouping, drew on a wealth of gay organising and campaigning experience, and this was crucially important. But the emergence of the dozens of other voluntary bodies that followed owed as much to the sense of identity provided by the ties and networks of the community as a whole than to any previous activist experience. Individuals were confirming their sense of common identity through involvement in the fight against HIV and AIDS. At the same time, many who were HIV positive or had been diagnosed with AIDS were affirming new identities, as 'Body Positive' or 'People with AIDS'.[37]

This sense of identity and belonging was crucial to the other major development within the gay community in the early 1980s, the adoption of a regime of what became known as 'safer sex'. It has been suggested that it was precisely the development of a resilient sense of self-esteem that was the 'sine qua non of safer sex education', and this has been confirmed by detailed studies.[38] The idea of safer sex had emerged in the early years of the American epidemic, and became central to the initial work of voluntary bodies and to the coverage of the issue in the gay press. There were clear signs of the success of safer sex campaigns by the mid-1980s, with a substantial drop in the incidence of sexually transmitted diseases amongst gay men. The detailed reasons for this are unclear, and there were clear variations in the sexual behaviour of gay men. It seemed likely that it was the urban gay man who was most likely to adopt explicit safer sex guidelines, with self-identification as part of the gay community as a crucial factor, and a sense of equality between partners as perhaps a vital element.[39]

The response of the gay community, and the major voluntary effort it sustained, was an expression of concern and involvement. It was also necessary in the absence of an appropriate official response until 1986. There is now well-documented evidence for the gradual creation of a 'policy community' around the health crisis in the years running up to the adoption of an official government strategy in late 1986, which drew on the expertise of leading figures in genito-urinary medicine, public health officials and activists largely drawn from the gay community. The outlines of what was to become the government response – an emphasis, in the absence of a likely 'cure', on prevention and health education – emerged, building on a much older tradition of public health policy which had its origins in the responses to diseases such as typhoid and cholera in the early days of industrialisation and urbanisation.[40]

On the other hand, it is difficult not to conclude that the association of AIDS with homosexuality, and to a lesser extent with other forms of social marginality, with all the historical baggage which these factors brought, determined governmental responses throughout the 1980s, particularly in the light of the moral panic in the early years. There was virtually no government response until 1984, when it intervened to secure the blood supply from contamination. It was 1986 before the first major initiative was taken directly by the government, which included the powers to detain people who were highly infectious (though these powers were rarely if ever used). Half of the fifty-nine parliamentary questions on AIDS in 1984–5 dealt with the blood supply, followed by drugs.[41] It is not to minimise the threat of HIV transmission from these sources to note the extraordinary disparity between the actual problem, amongst homosexual men, and the political priorities this suggests. It was to be November 1986 before there was a major House of Commons debate on the subject, four years after the first British deaths.

Two points need to be made. The first is that the government was operating in a situation that was widely perceived to be a gay crisis, at a time when as a result homosexuality was becoming deeply unpopular. The surveys of sexual attitudes during the 1980s are clear on this. The British Social Attitudes Survey for 1987 found that public opinion had become marginally less discriminatory towards homosexuality since 1983, with a greater acceptance also that lesbians and gay men should not be banned from certain professions. But when asked if they approved of 'homosexual relationships', there was evidence of a significant increase in hostility. In 1983, 62% had censured such relations; in 1985, 69%;

and in 1987, 74%. There was countervailing evidence also. A 1988 Gallup Poll for the *Sunday Telegraph*, whilst reporting that 60% of those sampled believed that homosexuality was not an acceptable lifestyle, observed that 50% of those under twenty-five were accepting.[42] It is also worth noting that all these surveys of opinion reported increased disapproval of extra-marital sexual relations, suggesting that what was happening was not only a reaction against homosexuality, but a reassertion of more conventional family values amongst significant sections of the population. Nevertheless, it is clear that AIDS was affecting the acceptability of homosexuality, and there was no great public support for more liberal policies towards lesbians and gays.

The second point that needs underlining is that the Thatcher government was highly sensitive to morally conservative currents of opinion. Even as the government was formulating a more considered policy towards the AIDS crisis in late 1986, the Secretary of State for Education was engaged in a complex campaign to prevent schools from providing positive images of homosexuality in response to conservative fears that left-wing local authorities were promoting homosexuality 'on the rates'. And this policy orientation was central to the government's strongest intervention on the subject during the 1980s: the banning by the Thatcher government of 'the promotion of homosexuality' by local authorities through what became known as 'Section 28' of the Local Government Act of 1988.

Behind the specific political context (in particular a government willingness to embarrass the Labour opposition over its ambiguous support for gay rights) was a deeper issue, a concern precisely with the challenge posed to 'traditional family values' by the claim to legitimacy by homosexuals. The famous neologism embodied in Section 28 – rejecting homosexuality as a 'pretended family relationship' – signalled that the claims of the lesbian and gay community in their fullness could not be accepted, because they were outside, antithetical to, the family. Despite the fervent advocacy of the more right-wing supporters of Section 28, this did not represent a challenge to the 1967 settlement, narrowly interpreted. There was no attempt to make homosexuality illegal. It did, however, challenge the claims of the vastly expanded lesbian and gay community as it had developed since 1970. 'Privacy', as far as homosexuality was concerned, was to be narrowly defined according to the interpretation of 1967. Anything beyond that was seen as a threat to the publicly sanctioned private sphere of the family endorsed by the conservative moral discourse of the 1980s.[43]

But even as the government supported what was widely seen as a repressive measure, it had specifically to exclude information about AIDS from its provisions. This highlights the difficulty of policy formation concerning sexuality in a complex society. For the new AIDS policy adopted in 1986 had assumed the need to promote sex education as the only way of halting the threatened epidemic. Implicitly, that meant the co-operation and involvement of the community most at risk, the gay community, a policy that was anathema to the ideologues behind the Thatcherite project.

The new government policy when it came did largely follow the developing policy consensus. The government in practice adopted traditional public health policies aimed at prevention rather than the more punitive policies of detention and segregation advocated by some of its supporters. The simple reason for this was that there appeared to be no practical alternative that would achieve widespread acceptability.[44] The advice that the Health Secretary offered to the nation – to use condoms, and avoid needle sharing – was not only sensible, it was essential. Only a public education campaign to increase awareness of HIV and AIDS, it was believed, would change people's behaviour. This new policy was undoubtedly inspired by the threat of a heterosexual epidemic, which had been dramatised by the publication of the US Surgeon-General's report on AIDS in October 1986. This, combined with mounting evidence that HIV was spreading in the 'heterosexual community' in Britain, propelled the new policy. It made it possible for the proponents of the developing policy and medical consensus to seize the ears of ministers; and it provided ministers, wary of a volatile public opinion and a raucous press, with the opportunity to make a radical departure. Five years into the crisis, AIDS had achieved the 'critical mass' to put it at the top of the policy agenda.

But there were multiple ironies in the policy departure. The policy adopted was basically one of sex education, at a time when the government was elsewhere pursuing a policy of redefining and restricting sex education, by taking it out of the hands of the despised local education authorities and giving responsibility largely to parents, who were thought likely to be more conservative. In part, too, the government was building on the achievements of the voluntary sector, largely led by the gay community which its policies otherwise sought to undermine.

The policy shift in 1986 signalled a new determination on the part of the government to manage the crisis, using by and large the traditional methods of what has been called the 'biomedical elite'. Yet once the period of 'emergency' passed, and crisis management became routinised, there were signs that the government's moral preoccupations had not changed. Hard on the heels of speculation that the heterosexual threat had been exaggerated in 1989, the special AIDS education unit of the Health Education Authority was disbanded, the Cabinet sub-committee overseeing the policy was wound up and Mrs Thatcher personally vetoed government support for a major academic study of sexual behaviour, designed to explore patterns of behaviour likely to facilitate spread of HIV. The media, not only the tabloids, seized the opportunity to state as a fact that AIDS was still a gay disease, and not a real heterosexual threat. It was hard to avoid the conclusion that for many people AIDS only mattered if it was a heterosexual problem.[45]

This certainly was the perception in the community still most at risk. There was a deep sense of frustration amongst lesbian and gay activists, confirmed by the passing into law of Section 28, that gave rise in the late 1980s to a new militancy in the HIV/AIDS and gay communities. A direct action grouping, ACT-UP (AIDS Coalition to Unleash Power), was established in 1989, echoing the American organisation set up in New York in 1987, and deliberately re-calling the militant gay activism of the early 1970s. A number of individuals who had been heavily involved in the earlier voluntary effort gave their support to the new venture, out of a sense that moderation and discreet behind the scenes lobbying had not fundamentally changed government attitudes.[46]

This seemed to be confirmed by an apparent increase in anti-gay prejudice and random violence following the passing of Section 28. By the end of the decade, there was also evidence that prosecutions for consensual homosexual offences had reached a new high (comparable with the previous high total in 1954, before the establishment of the Wolfenden Committee). New government initiatives in 1990/1, threatening to increase penalties for homosexual offences through the Criminal Justice Bill, and attempting to prevent lesbians and gay men from adopting children, sparked widespread opposition and the emergence of new militant lesbian and gay groupings, such as Outrage.[47]

Yet the paradoxical result of the first decade of AIDS was that homosexuality had achieved a voice as never before. Following extensive gay lobbying and activism, the penalties in the Criminal Justice Bill were modified, and new liaison procedures with the police were established. The new Prime Minister, John Major, had a much publicised meeting with a leading member of the gay community. In part such successes were the result of that 'legitimisation through disaster' which Altman has seen as a characteristic of the AIDS crisis.[48] As open lesbians and gays were drawn into policy formation and service delivery, as knowledge about gay lifestyles, and sexual practices, spread as a result of discussions of HIV and AIDS, so the homosexual community achieved a new openness and public presence. There was even some evidence that the 'blip' in public acceptability of homosexuality in the mid-1980s caused by the fear of AIDS had been overcome, with a small but important growth of support. Margaret Thatcher, despite AIDS and her conservative moral agenda, had in fact presided over a considerable growth in the self-confidence and social weight of the lesbian and gay community.

Yet the boundaries between acceptable and unacceptable sexual behaviour remained fluid and indeterminate and homosexuality remained ambiguously on the margins of social life, its acceptability still in doubt. Ambiguity was the hallmark also of government policy. During the 1980s there can be no doubt that government was constrained by its moral agenda. That did not stop the development of coherent policies by the policy and medical establishment, nor their implementation at national and local level when the crisis seemed acute. But the national policy was implemented in a climate of anxiety which the government's own moral agenda did little to alleviate, and that inevitably had a major impact on how the policy developed.

Meanwhile the health crisis ground on. Though the majority of deaths from AIDS by the beginning of the 1990s were still amongst gay men, the evidence of the underlying HIV epidemic suggested the pattern was beginning to change, with the rate of reported infection rising most rapidly amongst women. It was estimated that by the year 2001, 4,800 men and 1,200 women would die from AIDS annually; by 2011 the annual total would rise to 7,000. HIV, it seemed, would be increasingly a problem for heterosexuals, for women and for black people.[49] By the early 1990s there was evidence that the heterosexual spread was in large part amongst drug users and people from Africa, ominously echoing the development of the epidemic in the USA. But whatever the roots of transmission, the virus was slowly entering the heterosexual population. Once again, the government established a ministerial AIDS action group. Clearly the crisis was not over; in some ways it was still to come, with unpredictable implications for the future regulation of sexuality.

The histories I have outlined demonstrate the unpredictability and complexity of responses when a society is confronted by an unexpected and in many ways unprecedented crisis. In confronting the unpredictability of events 'History' is called upon to offer remedies. These could be drawn from a self-conscious history of resistance (the response of the gay community); from a history of public health (the response of the medical elite); or from a moral history which evoked a value system that probably by this time did not command widespread support, and which underlined a sensitivity to the dangers of rushing too far ahead of public opinion (by and large, the response of the Thatcher government during the 1980s). This suggests the key conclusion: the regulation of sexuality cannot be understood through a monocausal account. On the contrary, it reveals the interplay of diverse forces, burdened (like AIDS) by a multiplicity of often incompatible histories.

NOTES

1 For discussions of the multiple histories of AIDS, see Elizabeth Fee and Daniel M. Fox (eds.), *AIDS: The Burdens of History* (Berkeley, 1988), and Elizabeth Fee and Daniel M. Fox (eds.), *AIDS: The Making of a Chronic Disease* (Berkeley, 1992).

2 For a fuller development contextualisation of the points made here, see Jeffrey Weeks, *Sexuality and its Discontents: Meanings, Myths and Modern Sexualities* (London, 1985); and *idem*, *Sexuality* (Chichester and London, 1986).

3 The *locus classicus* of constructionist arguments is Michel Foucault, *The History of Sexuality*, vol. I: *An Introduction* (London, 1979). This little book made a major

impact, however, because it fed into theoretical debates already stimulated by the development of what was originally a 'grass-roots history', by feminist and lesbian and gay historians. For a general discussion of these developments, see Jeffrey Weeks, 'Sexuality and history revisited', in Lynn Jamieson and Helen Corr (eds.), *State, Private Life and Political Change* (Basingstoke and London, 1990), 31–49. For a sympathetic but appropriately critical overview of the various arguments, see Carole S. Vance, 'Social construction theory: problems in the history of sexuality', in Anja von Kooten Niekerk and Theo van der Meer (eds.), *Which Homosexuality?: Essays from the International Scientific Conference on Lesbian and Gay Studies* (Amsterdam and London, 1989).

4 Foucault, *The History*; Jeffrey Weeks, *Sex, Politics and Society: The Regulation of Sexuality since 1800* (Harlow, 1st edn, 1981, 2nd edn, 1989).

5 On the impact of the syphilis epidemic, see Judith R. Walkowitz, *Prostitution and Victorian Society: Women, Class and the State* (Cambridge, 1980).

6 For major contributions on this debate, see the essays in Edward Stein (ed.), *Forms of Desire: Sexual Orientation and the Social Constructionist Controversy* (New York and London, 1990).

7 See, for example, the discussion of this in Weeks, *Sexuality and its Discontents*, chapter 3.

8 On the ever-accelerating rapidity of social change, as the 'juggernaut of modernity' gathers speed, see Anthony Giddens, *The Consequences of Modernity* (Cambridge, 1990).

9 See Weeks, *Sex, Politics and Society* (1989 edn), chapter 15.

10 See the essays in Stuart Hall and Martin Jacques (eds.), *The Politics of Thatcherism* (London, 1983) and Ruth Levitas (ed.), *The Ideology of the New Right* (Oxford, 1986).

11 For a conservative view of the period, see Christie Davies, *Permissive Britain* (London, 1975). For a more radical analysis of the period see National Deviancy Conference (ed.), *Permissiveness and Control. The Fate of Sixties Legislation* (London, 1980).

12 Home Office and Scottish Home Department, *Report of the Committee on Homosexual Offences and Prostitution*, Cmnd 247 (London, 1957).

13 Weeks, *Sex, Politics and Society* (1989 edn), chapter 13. On the debates leading to the passing of the Sexual Offences Act 1967, which partially decriminalised male homosexuality, see Stephen Jeffery-Poulter, *Peers, Queers and Commons. The Struggle for Gay Law Reform from 1950 to the Present* (London, 1991). For a comparison with the rights-based developments in the USA during the same period see, Thomas B. Stoddard and Walter Rieman, 'AIDS and the rights of the individual: towards a more sophisticated understanding of discrimination', in Dorothy Nelkin, David P. Willis and Scott V. Parris (eds.), *A Disease of Society: Cultural and Institutional Responses to AIDS* (Cambridge, 1991), 241–71.

14 Ronald Butt, 'Lloyd George knew his followers', *Times*, 19 September 1985.

15 Jeffrey Weeks, *Coming Out: Homosexual Politics in Britain from the Nineteenth Century to the Present* (2nd edn, London, 1990), Part 5: 'The Gay Liberation Movement'.

16 The relation of these polarised *political* positions to actual public attitudes and behaviour is a complex one. Broadly, I would argue, there was a long term

'liberalisation' and 'secularisation' of attitudes, that continued despite AIDS and the dominance of a morally conservative government in the 1980s. See my *Sexuality*, and *Sex, Politics and Society* (1989 edn), chapter 15.

17 Stuart Hall, *The Hard Road to Renewal. Thatcherism and the Crisis of the Left* (London, 1989).

18 For a perceptive account of Mrs Thatcher's moral politics, based on her address to the General Assembly of the Church of Scotland in 1988, see Jonathan Raban, *God, Man and Mrs Thatcher* (London, 1988).

19 Martin Durham, *Sex and Politics: The Family and Morality in the Thatcher Years* (Basingstoke, 1991).

20 Anna Marie Smith, 'A symptomology of an authoritarian discourse. The parliamentary debates on the prohibition of the promotion of homosexuality', in *New Formations. A Journal of Culture/Theory/Politics*, 10 (Spring 1990), 41–65.

21 On the early American reaction to the burgeoning epidemic see Dennis Altman, *AIDS and the New Puritanism* (London, 1986), published in the USA as *AIDS in the Mind of America* (New York, 1986).

22 Weeks, *Coming Out*, chapter 17. For international comparisons, see Barry D. Adam, *The Rise of a Gay and Lesbian Movement* (Boston, Mass., 1987).

23 Gillian E. Hanscombe and Andrew Lumsden, *Title Fight: The Battle for Gay News* (London, 1983).

24 On the situation in the USA in the late 1970s and early 1980s, see Dennis Altman, *The Homosexualization of America, the Americanization of the Homosexual* (New York, 1972).

25 Weeks, *Coming Out*, chapter 15.

26 On the importance of relationships in the gay community, see my essay 'Male homosexuality in the age of AIDS', in Jeffrey Weeks, *Against Nature: Essays on History, Sexuality and Identity* (London, 1991), 100–13.

27 Speech of 27 March 1982.

28 On these themes, see, for example, the essays in Tessa Boffin and Sunil Gupta (eds.), *Ecstatic Antibodies: Resisting the AIDS Mythology* (London, 1990). On the 'sense of an ending', particularly in relation to AIDS, see Susan Sontag, *AIDS and its Metaphors* (London, 1989); and Elaine Showalter, *Sexual Anarchy: Gender and Culture at the Fin de Siècle* (London, 1991). On difference and identity, see the essays in Jonathan Rutherford (ed.), *Identity: Community, Culture, Difference* (London, 1990).

29 Nelkin, Willis and Parris (eds.), *A Disease of Society*, p. 3.

30 I first used the concept in relation to AIDS in 1985 in *Sexuality and its Discontents*, p. 45. The concept has been criticised by Simon Watney, 'AIDS, "moral panic" theory and homophobia', in Peter Aggleton and Hilary Homans (eds.), *Social Aspects of AIDS* (London, 1988), 52–64; and by Philip Strong and Virginia Berridge, 'No one knew anything: some issues in British AIDS policy', in Peter Aggleton, Peter Davies and Graham Hart (eds.), *AIDS: Individual, Cultural and Policy Dimensions* (London, 1990), 245–7.

31 On media response, see Simon Watney, *Policing Desire: Pornography, AIDS and the Media* (London, 1987); and Kaye Wellings, 'Perceptions of risk – media treatments of AIDS', in Aggleton and Homans (eds.), *Social Aspects of AIDS*, 83–105.

32 See the discussion in Jeffrey Weeks, 'Love in a cold climate', in Aggleton and Homans (eds.), *Social Aspects of AIDS*, 10–19.

33 Susan Sontag, *Illness as Metaphor* (New York, 1978).

34 All these incidents can be documented in the press between 1983 and 1986.

35 'The real plague is panic', leader column, *Guardian*, 19 February 1985.

36 See Albero Melucci, *Nomads of the Present: Social Movements and Individual Needs in Contemporary Society* (London, 1989) and Anthony P. Cohen, *The Symbolic Construction of Community* (Chichester, London and New York, 1985).

37 For some discussion of the voluntary response, see Strong and Berridge, 'No one knew anything: some issues in British AIDS policy', and Zoe Schramm-Evans, 'Responses to AIDS, 1986–1987', in Aggleton, Davies and Hart (eds.), *AIDS: Individual, Cultural and Policy Dimensions*, and Virginia Berridge, 'The early years of AIDS in the United Kingdom 1981–6: historical perspectives', in T. Ranger and P. Slack (eds.), *Epidemics and Ideas* (Cambridge, 1992).

38 Simon Watney, 'Safer sex as community practice', in Aggleton, Davies and Hart (eds.), *AIDS: Individual, Cultural and Policy Dimensions*; and Simon Watney, 'AIDS: the second decade: risk, research and modernity', and Mitchell Cohen, 'Changing to safer sex: personality, logic and habit', in Peter Aggleton, Graham Hart and Peter Davies (eds.), *AIDS: Responses, Interventions and Care* (London, 1991).

39 Ray Fitzpatrick, Mary Boulton and Graham Hart, 'Gay men's sexual behaviour in response to AIDS', in Peter Aggleton, Graham Hart and Peter Davies (eds.), *AIDS: Social Representations, Social Practices* (London, 1989); Ray Fitzpatrick, John McLean, Mary Boulton, Graham Hart and Jill Dawson, 'Variations in sexual behaviour in gay men', in Aggleton, Davies and Hart (eds.), *AIDS: Individual, Cultural and Policy Dimensions*; and Cohen, 'Changing to safer sex'. It is worth noting here that by the end of the 1980s there were ominous signs that younger gay men, identifying HIV as a disease of older men, were abandoning safer sex; and the rates of sexually transmitted disease (STD) infection showed signs of increasing once again. One London hospital noted twice the rates of gonorrhea infection in the first six months of 1990 as in the whole of 1989 (*Independent on Sunday*, 14 October 1990). Clearly the adoption of safer sex, though uneven, was much greater in the gay community than elsewhere, with heterosexual men proving particularly resistant to its messages (see Tamsin Wilton and Peter Aggleton, 'Condoms, coercion and control: heterosexuality and the limits to HIV/AIDS education', in Aggleton, Hart and Davies (eds.), *AIDS: Responses, Interventions and Care*). But another history, that making important generational differences within the gay community, was apparently reasserting itself.

40 V. Berridge and P. Strong, 'AIDS policies in the UK: a study in contemporary behaviour', *Twentieth Century British History*, 2, 2 (1991), 150–74; Berridge, 'The early years of AIDS in the United Kingdom'.

41 Berridge, 'The early years of AIDS in the United Kingdom'.

42 Roger Jowell, Sharon Witherspoon and Lindsay Brook, *British Social Attitudes: The 1986 Report* (Aldershot, 1988); *Sunday Telegraph*, 5 June 1988.

43 On the background to Section 28 see Smith, 'A symptomology of an authoritarian discourse'; also my essay 'Pretended family relationships', in Jeffrey Weeks, *Against Nature* (London, 1991).

44 See Berridge and Strong, 'AIDS policies in the UK', and Strong and Berridge, 'No one knew anything: some issues in British AIDS policy'.

45 See 'PM angers doctors by axing AIDS study', *Guardian*, 11 September 1989; 'Thatcher disbands Cabinet AIDS team', *Sunday Correspondent*, 17 September 1989.

46 Tony Whitehead, 'The voluntary sector: five years on', in Erica Carter and Simon Watney (eds.), *Taking Liberties: AIDS and Cultural Politics* (London, 1989).

47 See, for example, Labour Campaign for Lesbian and Gay Rights, *Emergency Briefing on Paragraph 16 and Clause 25* (London, 1990); 'Not fit to foster', *Pink Paper*, 5 January 1991; Jayne Egerton, 'Gay parents: nothing natural', *New Statesman and Society*, 16 November 1990; Sean O'Neill, 'Are the police looking the other way', *The Independent*, 18 December 1990; Nick Cohen, 'MPs oppose tough court penalties for homosexuals', *The Independent*, 10 January 1991; GALOP (Gay London Policing Project), *Annual Report* (London, 1990); 'Gay protest sealed with a kiss', *The Independent*, 6 September 1990; and '"Outing group" to name MPs as homosexual', *The Independent*, 29 July 1991.

48 Dennis Altman, 'AIDS and the reconceptualization of homosexuality', in van Kooten Niekerk and van der Meer (eds.), *Which Homosexuality?*

49 *OPCS Monitor*, PP2 91/1; Chris Mihill, 'AIDS figures prompt race backlash fears', *Guardian*, 9 August 1991.

2

Public health doctors and AIDS as a public health issue

JANE LEWIS

Most of the literature on HIV infection makes at least passing reference to 'public health'. However, the meaning of the term varies enormously. The public health implications of AIDS may be identified as the ways of protecting the population from infection, or, especially in the USA, may raise the issue of how to provide health care services for persons with AIDS within a badly fragmented system that offers only limited access. The public health issues arising from HIV are usually agreed to cover its epidemiology, to which disease control centres in both Britain and the USA have made the major contribution, and also the controversial debates arising from the interpretation of epidemiological data, which have focused on the protection of civil rights in face of measures to test for and control the spread of the infection. The behavioural changes believed to be necessary to prevent the infection may also be referred to under the heading of public health education. The lack of clarity that marks the discussion of public health in the literature merely reflects the wide-ranging – some would say, less flatteringly, 'rag-bag'[1] – nature of public health ideology and practice in the mid- and late twentieth century. Since the heroic battles of the nineteenth century for clean water and sanitation, and against infectious disease, the identity of public health as a specialty and in its relations to medicine has been far from clear. The extent to which its practice has been effective in promoting the health of the population has also been called into question by both contemporaries and historians.[2]

Public health doctors have experienced major difficulties in taking up a collective as opposed to an individualist approach to the health needs of the population vis à vis both the rest of the medical profession and government. Within the medical profession, British public health doctors have occupied a low status throughout the twentieth century and, since the 1974 and more especially the 1984 reorganisations of the National Health Service (NHS) have become increasingly hard to identify as a professional body. In the USA, the public health establishment is more readily identifiable and specialists in infectious disease have continued to have good career prospects, even though public health has become a much more interdisciplinary endeavour than in Britain. As an infectious disease, AIDS was, initially at least, perceived to call on the old tradition of public health expertise and the advice of public health practitioners was actively sought. Towards the end of the 1980s, the modelling of HIV infection underwent a significant change. The problem of managing persons with AIDS was increasingly viewed in relation to the management of chronic disease more generally. At the same time, the basis of prevention moved from an overwhelming emphasis on lifestyle prevention, in the sense of encouraging change in individual sexual behaviour, to a recognition of the problems in devising effective preventive measures among populations who could already be classified as materially disadvantaged in a number of respects.[3]

This chapter seeks, first, to chart the way in which the shift in the modelling of AIDS over a single decade has in fact mirrored the shift public health doctors have been struggling to make since the late nineteenth century in defining a role for themselves in a society no longer dominated by infectious disease. The changing meaning of health promotion and the prevention of disease, and the relationship of public health practice to health care delivery, have long been issues for public health. In Britain, AIDS posed a challenge to a public health profession that was severely demoralised. In making a response, public health also sought yet again to redefine its role. The last part of this chapter examines the extent to which public health in its revised form may be able to address the issues raised by AIDS as they are currently being defined. In many respects AIDS highlights the weaknesses of both public health and the NHS.

Modelling AIDS

Daniel M. Fox has recently described the way in which the diagrams that experts used to describe AIDS to audiences of health and policy professionals changed dramatically during the 1980s. For most of the decade they drew an iceberg, with only the top susceptible to treatment, but by 1989 they were drawing a time-line 'intersected by numerous and increasing opportunities for intervention'.[4] The perception of AIDS as a chronic disease requiring management was superseding the model that depicted it as a new plague.

Following the naming of AIDS and the perception of it as a novel, fatal and potentially widespread disease, responses were in large measure shaped by what Philip Strong has described as 'epidemic psychology'. He describes this as involving three components: an epidemic of fear, an epidemic of explanation and moralisation and an epidemic of action or proposed action.[5] Epidemiologists named the disease and epidemiologists continued to make the running during the first half of the 1980s (until the isolation of the HIV virus in 1984), as befitted the widespread fear of a new and apparently uncontrollable disease. The preoccupations revolved around establishing where the disease came from, how to protect endangered communities and how to put in motion research to develop vaccines and experimental cures.

The epidemiological data enabled researchers to describe the high incidence of the disease among the gay population. After that, it was open to a variety of interpretations. Epidemiology has historically been characterised (and some would argue restricted)[6] by its lack of theoretical context. There have been periods, for example in Britain during the late 1940s, when practitioners have attempted more firmly to tie the practice of epidemiology to social science methods. Thus J. N. Morris and Richard Titmuss stressed the importance of a multifactorial approach and of social variables in the study of factors inimical and favourable to health. But in both Britain and the USA the medical establishment proved suspicious of the social. Thus Morris and Titmuss's work on the epidemiology of rheumatic heart disease was criticised for emphasising the poverty factor too much and in the USA some epidemiologists set out explicitly to 'rescue' their discipline from such concerns and bring it back firmly into the 'laps of practising physicians'.[7]

While consideration of social factors could, in particular circumstances, lead to 'progressive' conclusions, especially when pitted against clinical or genetic factors, this was not necessarily the result. In the case of AIDS, the danger that social and moral judgements would be applied once the gay community was identified as a 'high risk group' was readily apparent. Thus the early years of AIDS saw suggestions that the disease resulted from 'immune overload' which was linked to recurrent bouts of sexually transmitted disease, which in turn could be attributed to promiscuity.[8] Such a chain of causality did little to illuminate the case of the middle-aged monogamous woman with AIDS that was to emerge in the mid-1980s. The search for cause proceeded from the identification of the group most at risk rather than from risk-bearing acts. This was arguably inevitable in the early stages of research, but it did not change as it logically should have done when the HIV virus was isolated, serving to redefine AIDS as a set of biomedical problems. Only when the heterosexual population was perceived as a population at risk did such a shift begin to take place.[9] As Ken Plummer has noted, the rhetoric of medicine and morality has been hard to distinguish;[10] the person with AIDS was constructed as the source of the disease rather than the sufferer.[11]

The second preoccupation of the plague model – the protection of endangered communities – thus immediately raised issues to do with the control of those infected with HIV, which both threatened to stigmatise the perceived risk group and to curtail their civil liberties. In the USA, the Institute of Medicine and the National Academy of Sciences summarised these issues as comprising: specific education for high risk groups, voluntary versus mandatory testing and reporting of test results, contact tracing, screening, regulations to close public places (as in the decision to close the gay bathhouses in San Francisco in 1984) and quarantine.

The impetus to compulsory public health measures was differently mediated in the USA and in Britain. In the latter, the voice of public health, embodied most influentially in the views of the Chief Medical Officer, Sir Donald Acheson, came out firmly against compulsion and appealed to the historical evidence in so doing. Dorothy and Roy Porter have reminded us of the historically weak alliance between public health and government in matters of compulsion. In the nineteenth century, success in imposing compulsory vaccination against smallpox and the Contagious Diseases Acts (which forced prostitutes to undergo medical examination for VD) was overthrown by repeal movements.[12] But as the Porters note, the most active component of medical opposition consisted of the GPs, who acted more out of a professional interest in preserving patient/doctor confidentiality than out of a regard for civil liberties. The position of public health has been historically ambivalent, population medicine offered a broad territory for population control. But on the whole the public health doctors' traditional concern with environmental factors has propelled them towards the educational end of the interventionist spectrum when it has been a matter of promoting change in the behaviour of individuals. Thus at the beginning of the twentieth century, when infant mortality was identified as one of the most significant public health issues, public health doctors eschewed the more Draconian features of extreme eugenic analysis in favour of 'educating mothers' in clinics, or, more intrusively, via health visitors.

In the context of AIDS, Simon Watney has identified two approaches, that of the 'terrorist' who, identifying an external invader, recommends testing, compulsion and even quarantine; and that of the 'missionary', who sees instead an evil spirit which thrives on immorality and possesses its victims, and recommends in response a return to traditional values.[13] It may be that it was the technical difficulty in securing exclusion that was most important in determining the approach to AIDS. The long incubation period, the very large numbers already infected before the epidemic was discovered, the initial absence of a quick and certain test and the huge numbers involved in international travel certainly all made the operation of quarantine regulations very difficult. Nevertheless, Watney's argument has the merit of signalling the elision between the moral and the social which has been historically present in public health policy and continues to be particularly prominent in the treatment of AIDS. In Britain, while public health doctors considered the issues of notifying, testing, screening and the like at length, a firm stand was taken against compulsion, notably by Acheson in, for example, both his evidence to the House of Commons Social Services Committee in 1987,[14] and his stand against the British Medical Association's (BMA) decision in 1987 to allow doctors to perform tests without consent, which was reversed the following year. While in 1984 regulations were changed to allow the compulsory removal of a person with AIDS to hospital, these were invoked only once. The position in the USA has been somewhat different, where, in Ronald Bayer's analysis, the public health voice found itself outflanked and where testing has been made mandatory for a range of employees of public institutions.[15]

The plague model of AIDS involved battles over what had been the public health territory of the nineteenth century – the control of epidemic, infectious disease. While the nature of the epidemiologists' multifactorial analysis of infection provided a space for a reactionary social politics, equally the public health profession's long consideration of environmental and social as well as biomedical factors served to moderate the policy response. It was not on the whole public health physicians who advocated that the legendary 1860s response to the cholera epidemic (consisting of the removal of the handle to the pump supplying infected water) be applied to the perceived source of AIDS, that is, the gay community.

As Fee and Fox have noted, the historical analogies to AIDS that were invoked were always epidemics such as smallpox and cholera, rather than, for instance, TB, which would have raised to mind rather different policy issues, involving problems of housing, poverty and community care.[16] The epidemic psychology of AIDS has, of course, been closely related to sexual politics and many commentators have made the connection between the fear of AIDS as a 'gay plague' and the great importance attached by New Right governments during the 1980s both to traditional sexual morality, and to the heterosexual two parent family as the motor of national stability and the chief provider of welfare.[17] However, towards the end of the 1980s expert models of HIV infection began to focus more on the problems of living with AIDS as opposed to the issues arising from the overwhelming fear of dying from the infection.

A number of factors account for the new construction of AIDS as a chronic disease. The isolation of the HIV virus meant that AIDS became redefined as a set of biomedical problems open to chemical resolution. Expensive treatments followed (principally involving the use of the drug AZT), which did not cure, but which made it possible to prolong life. The 'management' of the person with AIDS therefore became of increasing concern to the doctors and health service managers. At the same time, Virginia Berridge and Philip Strong have argued that in Britain the years after 1987 marked the assertion of the biomedical establishment's control over AIDS,[18] which contributed materially to the 'normalisation' of policy. During the first half of the 1980s, AIDS was increasingly perceived as a new kind of disease with a huge potential to kill. The British government became involved in a massive health education campaign in 1986 when the potential for infection among the heterosexual community was finally recognised. During these early years, Berridge and Strong have pointed to the existence of a relatively open 'policy community' around the Chief

Medical Officers at the then Department of Health and Social Security (DHSS). These were the years when 'no one knew anything'.[19] But between 1987 and 1989, expert opinion appeared to 'stabilise'. The 1989 House of Commons Social Services Committee commented on the scaling down of the figures for HIV infection during 1988;[20] in contrast to the Committee's report in 1987, AIDS was beginning to be perceived more as a long haul than an all-out battle. It was in 1987 too that the first estimate of the costs of caring for AIDS patients was published in the form of a letter to the *British Medical Journal*.[21] From 1987 the pattern of care for persons with HIV-related infection became more and more the focus of concern.

Just as it interlocked with the 1980s concern about 'the family', so AIDS also entered the debate over community care. The 1987 Social Services Committee Report stressed the achievements of gay voluntary organisations in San Francisco in providing continuous care whereby the hospitalisation of persons with AIDS was reduced to an average of two weeks a year. The movement towards community care, begun in the 1960s as a humanitarian policy by those desiring to promote 'normalisation' for both the elderly and mentally ill, had by the 1980s become part and parcel of the government's desire to reduce public expenditure, notwithstanding constant warnings from Titmuss as early as the 1960s that good community care could not be provided cheaply. In 1981, in a White Paper on the elderly, government warned that increasingly care 'in' the community would have to mean care 'by' the community, meaning that the sources of care would increasingly be 'informal', whether in the form of family members or voluntary organisations.[22]

Within this framework, the San Francisco model, which relied primarily on voluntary effort, looked very attractive. Health authorities feared the conflicting pressures of, for example, the hospital needs of persons with AIDS versus those of the elderly[23] at a time of cash crisis, NHS reform and the uncertainty surrounding the future of special funding for AIDS.[24] After 1987, authorities began to produce plans which allowed for only two weeks in-patient care a year with an appeal to a 'multiagency strategy' to facilitate the provision of housing, nursing and domestic help.[25] The response by the gay community to the shifting perceptions of AIDS and AIDS policies has been ambivalent, the fear being that while the perception of AIDS as a chronic disease may help those living with AIDS, it might also make it more difficult to exact money for basic research. The pride in caring, perhaps made more explicit by the American gay community than the British,[26] was strong, but was moderated by the desire for help, which the focus on the needs of those living with AIDS might be expected to bring. However, such a hope has been tempered by a political climate unsympathetic to further public expenditure and the increasing realisation that care in the community raises needs that are broader than health and personal social services, including crucially income and housing.[27] In this sense, the work of tertiary prevention in relation to persons with AIDS demands attention to structural as much as to lifestyle change. In addition, the population of those with HIV infection had become by the end of the 1980s considerably broader than the gay community. Drug addicts in particular could not fall back on voluntary aid.[28]

The new model of HIV infection therefore raises crucial issues as to the level of provision and co-ordination of different types of care for very different groups of people with AIDS. The plague model, with its focus on the cause of infection and the prevention of disease among the well, ignored what the medical profession has long referred to as tertiary prevention, meaning the promotion of health among the chronically or terminally ill. Such a shift in the modelling of AIDS has therefore brought new issues regarding health care and education on to the agenda. There is, of course, as Fox has cautioned, no guarantee that the AIDS model will not change dramatically again.[29] As recently as 1988, Fox himself, together with Fee, argued that health services were experiencing difficulty in dealing with AIDS because it was an infectious disease rather than the kind of chronic condition late twentieth-century medicine was used to dealing with (an argument which seemed to carry the controversial implication that the delivery of health care had indeed become successfully geared to the care of chronic conditions).[30] There is no guarantee that the issues of compulsion associated with the plague model will go away. Indeed, if the AIDS population becomes increasingly poor and, compared to the gay community, less powerful in terms of its lobbying capacity, these matters may regain importance. But the issues surrounding those living with HIV infection are not likely to go away. The shifting model of AIDS has meant that public health expertise has no longer been the frontline source of advice in the way in which it was when the infection was perceived to have much in common with nineteenth-century battles against epidemics. Indeed, the more recent model throws into sharp relief the difficulties public health has experienced in redefining its role in relation to the more general patterning of disease as overwhelmingly chronic, and in relation to the meaning of prevention and promotion. Some thirty years ago the public health profession was roundly criticised for not doing enough to co-ordinate community care; it remains to be seen whether recent efforts to define its role will make it more flexible in its future response.

Models for public health

Throughout the twentieth century, British public health doctors have been engaged in a redefinition of their role. During the 1980s this process has been closely bound up with the response to AIDS, but it is useful to understand the ways in which it is but the latest episode in a long renegotiation of public health's position. Nineteenth-century public health practitioners tackled water companies and other vested interests, as well as governments, in order to secure social reform that would prevent infectious disease. But in the twentieth century it has not been easy to address the full range of social, economic and environmental variables, including income and housing as well as personal lifestyle and health education, that may be considered to play a part in determining health status. The political battles involved in promoting the people's health have proved much larger than those required to attack specific environmental causes of disease. As a medical specialty, public health could be surer of its ground in fighting disease than in the murkier waters of promoting health; the latter all too easily became bound up with improving welfare, something both government and the medical profession itself considered to be outside the doctor's mandate. Nor has it proved straightforward to redefine prevention in relation to chronic disease; while efforts were made to minimise the division between prevention and cure, effective strategies for promoting tertiary prevention were developed but slowly.

From the early twentieth century, public health was reined in to focus on prevention and promotion in relation to the individual. As a result, the extent to which such a focus necessitated a consideration of health service administration and/or planning, and how it differed from the work of other, much more powerful, medical specialties became pressing problems. I have argued elsewhere that in this climate the practice of public health became effectively determined by the tasks it managed to accrue rather than by a strong sense of purpose and direction.[31] Arguably, the three major efforts to rethink the position of public health, embodied in the focus on personal preventive medicine in the early part of the century, and the further efforts to introduce social medicine in the 1940s and community medicine in the 1970s, were not very successful. Broad agreement greeted the mapping of the late twentieth-century health field by landmark documents such as the Lalonde Report of 1974,[32] which identified the areas of environment, lifestyle, health services and biomedical concerns as crucial. However, public health has not been able to assert a leadership role over environmental as well as lifestyle issues, or indeed over the balance of the health services needed for communities.

At the end of the nineteenth century, scientific advances in bacteriology helped to redefine the kind of intervention appropriate for public health. Once it was realised that dirt *per se* did not cause infectious disease, the broad mandate of public health to deal with all aspects of environmental sanitation and housing as the means of promoting cleanliness disappeared. Germ theory deflected attention from the primary cause of disease in the environment and from the individual's relationship to that environment and made a direct appeal from mortality figures to social reform much more difficult.[33] Increasingly public health authorities focused on what the individual should do to ensure personal hygiene. Paul Starr has characterised the shift in the changing nature of public health work in the twentieth century as a move towards a 'new concept of dirt'.[34]

As a result of germ theory, the twentieth-century concept of dirt 'narrowed' and also proved considerably cheaper to clean up. Thus in addition to developments in medical science, there was a political imperative to a more limited, less costly, mandate for public health.

Sir George Newman, the Chief Medical Officer at the newly formed Ministry of Health in 1919 offered a new model for public health, insisting that it 'must give up the idea that health is comprised in sewerage, disinfection, the suppression of nuisances, the burial of the dead, notification and registration of disease, fever hospitals, and endless restrictive by-laws and regulations. Health springs from the domestic, social and personal life of the people'.[35] Newman argued for preventive medicine based on the individual, which would involve a closer integration between preventive and curative medicine. However, the importance that Newman attached to public health as clinical medicine of a special kind – 'applied physiology' focused on the individual – brought the practice of public health confusingly close to that of general practice. During the late 1920s, GPs began to protest that they were the proper people to be dealing with all matters of health maintenance and disease prevention in respect of individuals.

Even though this claim substantially undercut the new rationale that public health was using to justify its existence, public health doctors were not unduly daunted during the inter-war years. For, notwithstanding the low status of the public health doctor as a salaried employee of local government, the public health departments became the administrators of the various piecemeal health service initiatives of the inter-war period. This work, rather than the model of individual prevention offered by Newman, became the mainstay of their practice, although many of the services they administered involved some elements of personal preventive medicine. By 1939, local authorities were permitted to provide maternal and child health services; a school medical service, including clinics treating minor ailments; dentistry; TB schemes, involving sanatorium treatment, clinics and aftercare services; infectious disease, ear, nose and throat and VD services; and health centres, the most elaborate being that built by the Finsbury Borough Council in 1938. In addition, the Local Government Act of 1929 allowed local authorities to take over the poor law hospitals and, by 1938, the number of acute beds provided by them equalled that provided by the voluntary sector. Finally, the Cancer Act of 1939 placed responsibility for the development of local regional cancer schemes on the local authorities rather than on the voluntary hospitals.

Public health doctors threw themselves into the work of medical administration, especially in regard to hospitals, the hub of the medical world, with gusto. There was a limited amount of contemporary criticism to the effect that public health was neglecting the work of prevention in favour of 'pathology'. The editor of one of the specialty's journals commented crossly that 'much recent public health work seems to aim at converting it into a gigantic hospital'.[36] In the case of both diphtheria and TB, the two major infectious diseases of the period, there was the tendency for public health doctors to associate themselves with institutionally based treatment, rather than with either effective immunisation procedures for diphtheria, or the spectrum of care services needed for TB sufferers.[37] Historians have also pointed out the extent to which the lead in raising questions concerning the health status of the population during the 1930s was taken by political lobby groups, such as the Children's Minimum Council and the Committee against Malnutrition; social scientists, for example, Richard Titmuss's investigation of infant mortality in relation to socio-economic class; a small number of medical specialists, particularly obstetricians and gynaecologists concerned about the incidence of maternal mortality; and by voluntary groups and organisations outside the medical establishment, such as the Women's Health Inquiry and the founders of the Peckham Health Centre, who were concerned to develop a philosophy of health.[38] The annual reports of public health doctors tended to take an optimistic view of the health of the people, even in areas of high mass unemployment. In so doing there is little doubt but that doctors were telling the Ministry what it wanted to hear.

Public health doctors remained confident during these years that they would gain a central place in any national organisation of health services as a result of the increased number of tasks they had collected. The preoccupation of public health had become inward looking, with an eye firmly on the medical politics of who would control the delivery of health care services. The meaning of the prevention of disease and the promotion of health in the context of the mid-twentieth century did not figure largely as matters for debate. But with the National Health Service Act of 1946, public health lost control of many of the tasks it had acquired during the 1920s and 1930s. Not surprisingly, the NHS was not unified under the control of local authorities and salaried public health doctors. This left the specialty bemoaning the remnants that remained.

The attempt to introduce 'social medicine' into the universities during the 1940s offered a second model for public health practice and held out a promising looking life-line to the specialty, but ended in deepening the division between academics and practitioners. John Ryle, appointed the first professor of social medicine at Oxford in 1942, argued that social medicine extended the interests of public health and altered its emphasis. Whereas public health was concerned primarily with environmental and personal health services, social medicine tried to study man in relation to all aspects of his nature and nurture. Second, while public health was preoccupied with infectious disease, social medicine was concerned with the epidemiology of all diseases. And finally, social medicine took within its province the whole work of medical sociology, defined by Ryle as the work of social diagnosis and aftercare services.[39] In this model, public health was invited to make epidemiological work its main concern, with a view to elucidating the determinants of health and disease.

Most professors of social medicine were convinced that the public health service was old-fashioned in its approach. W. Hobson, professor of social and industrial medicine at the University of Sheffield, commented on the public health departments' 'woeful lack of data on which to base a scientific approach'.[40] But social medicine failed to have the kind of impact on the medical schools that the new professors of the subject hoped for. While the 1944 Inter-Departmental Committee on the Medical Schools talked enthusiastically of a radical reorientation of the medical curriculum and of the need for social medicine to permeate all medical school teaching, most schools reacted only by slightly modifying their departments of public health. Furthermore, the concept of social medicine was progressively narrowed down in order to stake a claim to academic respectability. Ryle's own work increasingly emphasised the links between clinical medicine and epidemiology at the expense of social science and health policy, and the importance of the study of 'social pathology' – the quantity and cause of disease – at the expense of the more radical and difficult aim of promoting health.[41] Public health practitioners reacted against both what they regarded as 'ivory tower' academic criticism of their work and the increasingly clinical focus of social medicine. After the NHS was set up, they veered once more towards looking for new services to administer, finding them in the form of ambulances, social work and nursing homes.

Since the First World War public health doctors had concentrated increasingly on the performance of tasks associated with the delivery of health services. Even in their reduced circumstances after 1948, they controlled large numbers of staff, including health visitors, sanitary inspectors and social workers. During the 1950s and 1960s all these groups exerted claims to professional independence, culminating most notably in the secession of social workers with the setting up of the social service departments according to the recommendations of the 1968 Seebohm Committee.[42] In particular, public health doctors proved once again vulnerable to the argument that their clinical preventive work could be done by GPs, and were hard-pressed to answer the charge that they had proved ineffectual in organising good community care.[43] Not for the last time, public health doctors found themselves at the mercy of institutional reform, which at the end of the 1960s sought to rationalise community care and social services around the social worker and the GP.

It was in this context that a third major effort to provide public health with a new rationale and direction – as community medicine – took place. The main initiator was Professor J. N. Morris, who had played a central role with Richard Titmuss in promoting the co-operation between medicine and social science that had been the hallmark of early social medicine. Morris believed strongly that public health practice should be grounded more firmly in the principles of modern epidemiology and lifestyle prevention. His textbook on epidemiology identified the major uses of the subject as historical study, community diagnosis, analysis of the workings of health services, analysis of individual risks and changes, the identification of syndromes and the completion of the clinical picture.[44] From this he evolved the concept of a community physician responsible for community diagnosis and thus providing the 'intelligence' necessary for the efficient and effective administration of the health service. The community physician would carry out the studies that would provide the basis for a discussion of rationing and other issues involving the 'morality of medical care'. With the entry of community physicians into the NHS at a constant level (something always denied to them as employees of local government), Morris also envisaged them overseeing the integration of the three parts of the service: general practice, hospitals and community medicine. Believing that a multicausal, epidemiological approach would ensure consideration of socio-economic and environmental variables and eliminate the danger of 'blaming the victim' for his or her illness, Morris built up examples around specific non-infectious diseases to emphasise the importance of co-operation between clinicians and community physicians, something that had also been important to Ryle. In regard to coronary heart disease, for example, he argued that the barriers between prevention and cure were crumbling and 'public health needs clinical medicine – clinical medicine needs a community'.[45]

From the beginning, government put more emphasis on the work of the new community physician in management of the health services than on his or her role as a specialist adviser using epidemiological skills; nor did government planning documents make any mention of prevention other than as it related to personal health services.[46] Most community physicians experienced considerable difficulty in adjusting to the positions that many were given on consensus management teams and to working with little support to provide specialist advice. Some found that they were expected to concern themselves only with health services in the community beyond the hospital and many others experienced a tension as to their accountability to the health authority on the one hand and to their populations on the other. Closely allied to the question of the community physician's accountability to the community as opposed to the NHS bureaucracy has been the responsibility some community physicians have felt to take up a broader mandate as spokespersons on the state of the people's health. While Morris had envisaged the community physician pursuing the 'applied physiology' first outlined by Newman early in the century and updated in the form of the 'lifestyle' approach, the Black Report on health inequalities drew attention to the need for a 'total and not merely a service-oriented approach to the problems of health'.[47]

The fortunes of community medicine were to a large extent bound up with the success or failure of the new NHS structure. While community physicians struggled to forge a role within it, both clinicians and government policy-makers tended to regard them as part and parcel of the new management structure of the service. When, in the 1980s, the concern of government became less the integration of the NHS and more the promotion of effective line management as a means to controlling spiralling costs, the role of the community physician faded from view. After general management was introduced in 1984, the community medicine establishment was reduced and the work allotted to community physicians varied widely from district to district. It was possible for energetic practitioners to prosper; the new emphasis on monitoring, for example, offered a new space for public health practice. But at the other (admittedly less common) extreme, community medicine virtually disappeared. Certainly, community medicine was not central in the way in which either the 1944 Inter-Departmental Committee on the Medical Schools or Morris had dreamed. It was sidelined with a much narrower remit. The role set out for the community physician was crucial for securing the public health, but by the mid-1980s, neither the community physician nor anyone else was performing it.

Public health and AIDS in the 1980s

At a time when community medicine faced declining credibility as a medical specialty the appeal engendered by AIDS to an earlier golden age of public health was attractive.

In 1986, the government set up a committee of inquiry into the future development of the 'public health function'. This followed two major outbreaks of infectious disease: salmonella at Stanley Royd Hospital in 1984 and Legionnaires' disease at Stafford in 1985. Reports on both episodes pointed to a decline of available expertise in environmental health and in the investigation and control of communicable disease. These had been the traditional concerns of public health, but the emphasis within the specialty had long been placed elsewhere. After 1974, the training of community physicians, one of whom remained the named medical officer for environmental health in each health district, gave little time to infectious disease.

The committee of inquiry was chaired by Sir Donald Acheson, who had already made explicit the connection he perceived between AIDS and earlier epidemics in his *Annual Report* for 1984: 'While the scourge of smallpox has gone and diphtheria and poliomyelitis are at present under control, other conditions such as legionellosis and AIDS have emerged. The control of the virus infection (HTLV III) which is the causative agent underlying AIDS is undoubtedly the greatest challenge in the field of communicable disease for many decades.'[48] The committee of inquiry referred at length to the demoralised position of community medicine. After the introduction of general management in 1984, thirteen authorities had no community physician on the district management boards and community physicians were often to be found in posts with titles such as director of planning, director of service evaluation or director of service quality, jobs that did not necessarily require a medically qualified incumbent. Public health at district level had achieved little by way of a coherent response to AIDS. In one London district, for example, the introduction of general management had resulted in an erosion of the power of community medicine in favour of the district general manager.[49] Where community physicians played a central role, as in Bradford, it happened more by accident than anything else.[50]

The Acheson Report included a section on the challenge posed by AIDS and this was used as a major prop for an enlarged model for public health practice, which included the provision of epidemiological advice, lifestyle and environmental prevention policies, health promotion and the co-ordination of the control of communicable disease.[51] Of these, the importance of epidemiology in giving public health scientific legitimacy was stressed as much as by Ryle in the 1940s, or Morris in the 1960s and 1970s.[52] It provided, the report suggested, the basis for the causal analysis of health problems, the health needs of populations and the provision, organisation and evaluation of services. Again it was suggested that the challenge of AIDS required such 'scientifically based analysis';[53] the battle over the interpretation and use of the data remained unacknowledged.

In many respects the report had a strong 'back to the future' flavour. It recommended that the name community medicine be abandoned and that the specialty call itself 'public health medicine'. There was also a sense in which public health was seen to be reclaiming a well-known niche for itself in relation to infectious disease. It was recommended that health authorities assign executive responsibility for communicable disease control to a District Control Infection Officer, who in regard to AIDS would take responsibility for liaison with GPs, hospitals and local authorities, and who would chair the District Control of Infection Committee.[54]

It is not clear how helpful such retrenchment will prove in regard to meeting the challenge of AIDS. First, the redefinition of community medicine's task was designed in large measure to provide the weakened specialty of community medicine with a more secure position in medicine, hence the addition of 'medicine' to 'public health'. But as John Ashton pointed out in the *British Medical Journal*, this reduced the likelihood of an effective intersectoral approach.[55] For while the report recognised the necessity of such an approach, the suggested membership of the District Control of Infection Committee was confined to the health district and to the medical profession, the only exception being the environmental health officer employed by the local authority. As Ashton remarked, in the case of AIDS this could do little to promote much needed liaison with voluntary organisations and the media.

Second, the addition of provisions designed to beef up the role of public health in preventing infectious disease has in part been overtaken by the changes in the modelling of AIDS. These have brought to the fore the problem of co-ordinating the continuous care that persons with AIDS need and the extent to which tertiary prevention raises issues of social and economic well-being as much as the need for lifestyle changes. On the former, several studies published in the late 1980s have commented as to the inadequacy of co-operation between health and social services and voluntary organisations in securing the full spectrum of care needed by persons with AIDS.[56] Beardshaw, Hunter and Taylor have noted that despite the emphasis on community care and prevention, most of the earmarked AIDS' money continues to go to the health authority in which most acute treatment is given.[57] In their research on six different sites, only one had succeeded in implementing joint planning to the point where a strategy had been accepted by all the principal local agencies. These findings point to the need for planning across the different parts of the health service and between community health and other services provided by local government and the voluntary sector. The 1974 job description for the community physician envisaged that they would undertake the planning across the full range of health services, but this (admittedly grandiose) vision faded swiftly. However, the lack of such planning for continuous care remains a major weakness, something that the failure to develop a fully fledged intersectoral approach in the Acheson Report will not help public health to remedy. It is possible that the 1990 NHS and Community Care Act may do more to promote change on this score and in so doing to bolster the position of public health. Arguably one of the most important parts of the legislation has been its stress on the importance of assessment for both health and social care, and in some, but by no means all, health districts, public health medicine has been asked to take the leading role in the work of assessing needs.

In his criticism of the Acheson Report, Ashton saw no reason to hope that public health doctors would be willing to address the wider social issues raised by tertiary prevention: 'Community physicians are keeping their heads down and avoiding contentious issues that affect public health . . . The public health voice on behalf of the homeless, the unemployed, and the poor and in defence of the National Health Service has been muted.'[58] In the case of AIDS, the issues of income and of providing safe housing of good design and with secure tenure have been raised with increasing frequency during the late 1980s, but there is little sign of public health deserting the focus on the individual that has characterised its preventive work since the early twentieth century. As Homans and Aggleton have argued, different understandings of health give rise to different preventive strategies: a predominantly biomedical understanding will tend to result in stress on the importance of changing individual behaviour, whereas a more social or holistic understanding will emphasise strategies based on community development and self-empowerment.[59] In this way, the failure to consider broader social and economic determinants of health may be linked to the failure to develop an intersectoral approach.

In the special edition of the *British Medical Journal* published to celebrate the journal's 150th anniversary, Roy and Dorothy Porter appealed to public health's heroic past and urged the specialty to resuscitate prevention and collective action, and to find the will to tackle governments in the manner of its nineteenth-century forebears.[60] Broadly speaking, this captures the spirit necessary to address the issues raised by AIDS, which have exposed the weakest points in health care provision. While it is not sufficient to advocate a return to the nineteenth-century model of public practice, a determination to consider social and environmental determinants of health and illness and to take issue with those in authority is necessary. However, it is not these aspects of public health's past that have inspired the model of practice offered by the Acheson Report.

NOTES

1 L. Jordanova, 'Review essay', *Social History*, 6 (1981), 371.

2 E.g., C. Webster, 'Healthy or hungry thirties?', *History Workshop Journal*, no. 13 (1982), 110–29.

3 This has been especially true of the USA, see Daniel M. Fox, 'Chronic disease and disadvantage: the new politics of HIV infection', *Journal of Health Politics, Policy and the Law*, 15 (1990), 341–55, but the tendency is the same in Britain with the increase in infection among drug users.

4 *Ibid.*, 344.

5 Philip Strong, 'Epidemic psychology: a model', *Sociology of Health and Illness*, 12 (1990), 249–59.

6 D. Roth, 'The scientific basis of epidemiology: an historical and philosophical enquiry', PhD thesis, University of California at Berkeley, 1976.

7 J. N. Morris and R. M. Titmuss, 'Health and social change I: the recent history of rheumatic heart disease', *Medical Officer*, 72 (1944); and J. N. Paul, *Clinical Epidemiology* (Chicago, 1958), 40.

8 Dennis Altman, *AIDS and the New Puritanism* (London, 1986), 35; and Hilary Homans and Peter Aggleton, 'Health education HIV infection and AIDS', in P. Aggleton and H. Homans (eds.), *Social Aspects of AIDS* (London, 1988), 155.

9 Gerald M. Oppenheimer, 'In the eye of the storm: the epidemiological construction of AIDS', in Elizabeth Fee and Daniel M. Fox (eds.), *AIDS: The Burdens of History* (Berkeley, 1988), 286.

10 Ken Plummer, 'Organising AIDS', in Aggleton and Homans (eds.), *Social Aspects of AIDS*, 28.

11 Erica Carter, 'AIDS and critical practice', in Erica Carter and Simon Watney (eds.), *Taking Liberties: AIDS and Cultural Politics* (London, 1989), 61.

12 Dorothy Porter and Roy Porter, 'The enforcement of health: the British debate', in Fee and Fox (eds.), *AIDS: The Burdens of History*, 107 and 114.

13 Simon Watney, 'Taking liberties: an introduction', in Carter and Watney (eds.), *Taking Liberties*, 20.

14 House of Commons, Social Services Committee, *Problems Associated with AIDS*, Minutes of Evidence, 182 – (i) (London, 1987).

15 Ronald Bayer, *Private Acts, Social Consequences. AIDS and the Politics of Public Health* (New York, 1989).

16 Elizabeth Fee and Daniel M. Fox, 'The contemporary historiography of AIDS', *Journal of Social History*, 23 (1989), 305.

17 See J. Weeks, 'Love in a cold climate', in Aggleton and Homans (eds.), *Social Aspects of AIDS*, 12; and Miriam David, 'Moral and maternal; the family in the right', in Ruth Levitas (ed.), *The Ideology of the New Right* (Oxford, 1986), 136–66.

18 Virginia Berridge and Philip Strong, 'AIDS policies in the UK: a preliminary analysis', in Elizabeth Fee and Daniel M. Fox (eds.), *AIDS: The Making of a Chronic Disease* (Berkeley, 1992).

19 Philip Strong and Virginia Berridge, 'No one knew anything: some issues in British AIDS policy', in Peter Aggleton, Peter Davies and Graham Hart (eds.), *AIDS: Individual, cultural and Policy Dimensions* (London, 1990).

20 Department of Health/Welsh Office, *Short Term Predictions of HIV Infection and AIDS in England and Wales*, Report of a Working Group (London, 1988).

21 Deirdre Cunningham and S. F. Griffiths to the editor, *British Medical Journal*, 295 (1985), 921.

22 J. Lewis, '"It all begins in the family": community care in the 1980s', *Journal of Law and Society*, 16 (1989), 83–96.

23 King's Fund Project Paper no. 68, *AIDS: Planning Local Services* (London, 1987).

24 Virginia Beardshaw, David J. Hunter and Rosemary C. R. Taylor, *Local AIDS Policies: Planning and Policy Development for Health Promotion*, Health Education Authority AIDS Programme papers no. 6 (London, 1990), 10.

25 E.g., Oxford Regional Health Authority, *Towards the Control of an Epidemic: Regional Policy and Strategy for HIV Infection, 1989–93*, consultation draft (Oxford, 1989).

26 See Cindy Patton's account of the USA in, 'The AIDS industry', and J. Weeks's comments on the differences in the British context in 'AIDS altruism and the New Right', both in Carter and Watney (eds.), *Taking Liberties*, 115 and 129.

27 Resource Information Service, *AIDS: The Issues for Housing* (London, 1987), and Alan Walker, 'Community care policy and AIDS', in Virginia Beardshaw (ed.), *AIDS: Can We Care Enough?*, report of a conference for World AIDS Day, 1988, organised by the National AIDS Trust in association with the King's Fund Centre (London, 1989), 49–52.

28 Nick Partridge, 'The role of AIDS-specific voluntary organisations', in Beardshaw (ed.), *AIDS: Can We Care Enough?*, 58–60.

29 Fox, 'Chronic disease and disadvantage'.

30 Elizabeth Fee and Daniel M. Fox, 'Introduction. AIDS, public policy and historical inquiry', in Fee and Fox (eds.), *AIDS: The Burdens of History*, 10.

31 Jane Lewis, *What Price Community Medicine? The Philosophy and Politics of Public Health since 1919* (Brighton, 1986).

32 Health and Welfare Canada, *New Perspectives on the Health of Canadians: A Working Document* (Ottawa, 1974).

33 N. Hart, *The Sociology of Health and Medicine* (Ormskirk, Lancs. 1985), 14–17.

34 Paul Starr, *The Social Transformation of American Medicine* (New York, 1982).

35 George Newman, *The Foundation of National Health*, the Charles Hastings Lecture (London, 1928).
36 'Preventive medicine in 1930', editorial, *Medical Officer*, 45 (1931), 1.
37 L. Bryder, *Below the Magic Mountain. A Social History of Tuberculosis in Twentieth-Century Britain* (Oxford, 1988).
38 Jane Lewis, *The Politics of Motherhood: Child and Maternal Welfare in England, 1900–1939* (London, 1980).
39 J. A. Ryle, *Changing Disciplines* (Oxford, 1949), 11–12.
40 W. Hobson, 'What is social medicine?', *British Medical Journal*, 2 (1949), 125.
41 Ryle, *Changing Disciplines*, 7.
42 PP, 'Report of the Committee on Local Authority and Allied Personal Social Services', Cmnd. 3703, 1967–8, p. 157.
43 'Medical Care', editorial, *Medical Officer*, 97 (1057), 104.
44 J. N. Morris, *The Uses of Epidemiology* (Edinburgh, 1969; 1st edn, 1957).
45 J. N. Morris, 'Tomorrow's community physician', *Lancet*, 2 (1969), 814.
46 Department of Health and Social Security, *Report of the Working Party on Medical Administrators* (London, 1972), para. 136.
47 P. Townsend and N. Davidson (eds.), *Inequalities in Health (*Harmondsworth, 1982), 41.
48 *Annual Report of the Chief Medical Officer of the DHSS for the Year 1984* (London, 1986), 35–7.
49 Ewan Ferlie and Andrew Pettigrew, 'Coping with change in the NHS: a frontline district's response to AIDS', *Journal of Social Policy*, 19 (1989), 191–220.
50 Dr Kathie Marfell and Jane C. Whitham, 'A public health response: the experience of Bradford', in Maryan Pye, Murkesh Kapila, Graham Buckley and Deirdre Cunningham (eds.), *Responding to the AIDS Challenge* (London, 1989), 131–42.
51 PP, *Public Health in England*. The Report of the Committee of Inquiry into the Future Development of the Public Health Function, Cm. 289 (London, 1988), para. 5.3.
52 *Ibid.*, para. 8.10.
53 *Ibid.*, 3.6.
54 *Ibid.*, paras. 7.16–17 and 7.25.
55 John Ashton, 'Acheson: a missed opportunity for the new public health', Leader, *BMJ*, 296 (1988), 231.
56 King's Fund Project paper no. 68, *AIDS: Planning and Local Services*, 26, and Andrew Bebbington and Pat Warren, *AIDS: The Local Authority Response* (Canterbury, 1988).
57 Beardshaw, Hunter and Taylor, *Local AIDS Policies*, 10.
58 Ashton, 'Acheson: a missed opportunity', 231.
59 Homans and Aggleton, 'Health education', 157.
60 Roy and Dorothy Porter, 'The ghost of Edwin Chadwick', *British Medical Journal*, 301 (1990), 252.

3

Politics and policy: historical perspectives on screening

BRIDGET TOWERS

Introduction

This paper grew out of the realisation that the governing context of my appraisal of contemporary AIDS policies was the historical material that I was dealing with in my research on tuberculosis policy and health education. The debates surrounding HIV serotesting had a deep resonance in the correspondence in the Public Record Office (PRO) files of the Ministry of Health dealing with policy formation on mass testing and health surveillance. Here too there was long, careful and critical consideration of the mandate and responsibility for the extension of routine health services into new territories. There was also concern at the Cabinet level about international co-operation in epidemiological data collection and the consequences of exclusionary immigration controls. I was struck too by the problems, both epistemological and practical, which the notion of 'presymptomatic illness' had posed for policy makers.

In saying this, I must, however, be cautious of the methodological trap of 'presentism'; i.e. attempting to interpret past actions and actors in terms of the cognitive structures, analytical paradigms and critical agendas of the present.[1] This is a particular danger for sociologists such as myself who look for the broader dynamics involved in policy changes over and above those which are situation specific. However, it would be overcautious in the extreme to fail to bring to the table of contemporary discussions the longer history of experience of creating preventive health programmes. I am of the belief that the historian's contribution can stand in its own right to furnish accounts and contexts and witness to the dimension of temporarity.

It was with this perspective that I looked in greater detail at four specific examples of screening programmes, in England, that were the subject of policy debate in the Ministry of Health during the last fifty years. These are: mass radiography for tuberculosis; ante-natal VD testing; paternity testing; and the medical inspection of aliens. In the second section of this paper I will briefly present these screening stories and in the final section I will attempt to draw one or two connections between them and the questions that non-historians have raised about the expansion of screening as a health measure, not just for HIV but for chronic disease and more recently for genetically transmitted conditions.

Mass radiography for tuberculosis was the first attempt to use the new technology of miniature mobile radiography for the early detection of tuberculosis by chest X Ray. Ante-natal VD screening was a proposal to expand the routine rhesus factor serotesting of pregnant women to include an 'added-on' Kahn test for VD. Paternity testing was the attempt to develop a new serotest as a routine procedure in affiliation proceedings; it was an example of the use of laboratory knowledge in the field of serotesting for forensic purposes. The medical inspection of aliens had a long history in early international public health but in the 1940s the increase in immigration led to a requestioning of the relationship between exclusionary screening for infectious diseases and screening for projective health care demand, this led to a shift in the function of the medical inspection as a regulatory element in immigration control.

All of these programmes were the subject of issue at a time of the radical restructuring of the Health and Welfare Services in the 1940s and early 1950s. They have to be seen in the light of major changes in the financing, administration and control of public services both at the Treasury level of departmental budget allocations and also lower down the various intradepartmental sectors.

Mass radiography for tuberculosis has to be situated in the context of the disappearance of a separate tuberculosis section of public health and its integration into the work of the Regional Hospital Boards. The development of serotesting has to be understood with reference to the reorganisation of the separate Laboratory Services and their complex relationship to the new hospital and primary health care services. It was also a time in which the political economy of a war-time state generated and facilitated new administrative systems which entailed the logistical capacity to innovate and deploy on a mass scale, as can be seen in the introduction of mass radiography to screen military manpower.

At such times of major change there are always occupational groups who take the opportunity to advance their interests and position, and during this period the development of new technologies and procedures was an integral element in conflicts over the defence of new and maintenance of old occupational monopolies. For instance in the case of the new mass radiography the strict regulation of the operation of the machinery was designed to maintain the old distinction between radiologists as medical professionals and radiographers as technicians. Here also the distinction between the traditional 'diagnostic' X Ray and the 'indicative reading' of the miniature film was made with an eye to demarcating the provinces of 'clinical diagnostic activity' and 'public health case-finding'.[2]

What is 'screening'? Foltz and Kelsey in their critical case study of the Pap Test for cervical cancer screening present an 'anchor' definition: 'the presumptive identification of unrecognized disease or defect by the application of tests, examinations, or other procedures which can be applied rapidly to sort out apparently well persons who probably have a disease from those who probably do not' (Foltz and Kelsey, 1978, p. 427).

This is the same basic definition from which the World Health Organisation (WHO) Global Health Strategy for the Year 2000 identifies criteria that all screening procedures should fulfil before they are applied to populations. However, it is not clear that working with a fixed definition like this is the most satisfactory procedure when dealing with historical material.

Stanley Reisler (1978a) in his review of its history treats screening as an emergent concept and does not himself offer an authoritative definition. He documents a development throughout this century of preventive medical services, which began with individual routine health 'check ups', developed into case finding through mass testing for infectious disease, expanded to cover periodic individual testing for chronic conditions and has ended up as full multiphasic screening operated as part of the regular menu of modern health care provided by employers and medical practitioners.

This question of definitions brings us directly to the theoretical issue of what is the 'object' of study in historical interpretations of policy. How far can we assume even a fixed composite of activities, actors and material objects which we can identify as constituting 'screening'? I come from a radical sceptical background which sees 'policy objects' as differentially constituted by different groups and would argue that the historian's task in the telling of policy stories is essentially about describing who is sitting around which tables talking to whom, using what language when the particular topic was on the agenda. I should not want to be held to some *a priori* definition of what screening 'actually is' and by that criterion adjudicate whether these were really examples of it. It seems to me that it is precisely the ambiguity and conflict in the giving of interpretive accounts by participant actors that is the policy discourse.

In 1940 Lord Dawson described mass radiography as 'sorting',[3] the Medical Research Council (MRC) in 1942 referred to it as 'sifting'[4] and by 1954 the Ministry of Health was tentatively using the term 'screening'.[5] The Welsh Hospital Board saw it as an integral part of modern routine health maintenance[6] whereas the Ministry of Labour saw it as an exclusionary measure for service pension entitlement.[7] The statisticians in the Ministry of Health saw ante-natal VD testing as prevalence monitoring;[8] and the Home Office saw paternity testing as forensic evidence gathering.[9]

In this paper I retain a flexibility of definition and see my task as charting the various ways in which these programmes and procedures were both legitimised and differentiated from traditional medical diagnostic practice.

The stories

Mass radiography for tuberculosis

The technology of miniature radiography appears to have been invented in 1936 and developed and implemented for medical use in North America. As a procedure for use in health examinations, the chest X Ray was first introduced in Britain as a military measure in 1940. It was later taken up for use on selected civilian populations; in the beginning by the Welsh Board of Health and later, on an experimental basis, by the Ministry of Health in England. It was then more widely deployed by the Ministry of Labour to cover all military recruits and by 1948 it had become a standard part of the Tuberculosis Service's repertoire of the new Regional Hospital Boards. Between 1936 and 1948 government's attitudes towards mass X Ray passed from low key acceptance to high enthusiasm.

The foundation of the British TB scheme based on a public health service organised around dispensaries, sanatoria and chest hospitals had been laid by the Astor Committee Reports of 1912 and 1913 but it was not until the issue of tuberculosis in the post-war period and the particular problem of ex-servicemen was raised by the Barlowe Report of 1919 that large-scale development funding was provided by Exchequer grants and a network of services was fully established.

Although there had been a long history during the inter-war years to expand community-based tuberculosis work, both in alliance with other public health and child welfare services, the Tuberculosis Service remained a separate and directly funded branch of public health. It had its own section and statistical bureau within the Ministry of Health and enjoyed the patronage of senior civil servants who found that their participation in the Tuberculosis section of the Health Committee of the League of Nations and the League of Red Cross Societies in Geneva provided a useful political base for British health policy initiatives to be legitimated and advanced both domestically and internationally (Howard-Jones, 1978). It was therefore not unusual to find that a foreign initiative in tuberculosis policy was enthusiastically considered; although it should be noted that another anti-TB measure popular in Europe, BCG vaccination, had been critically rejected.[10]

The initiative for mass radiography in a military capacity came from Lord Dawson in February 1940. In a private memo to the Chief Medical Officer of Health he expressed concern about the level of wastefulness caused by tuberculosis amongst enlisted men and pointed to the standard procedure of mass radiographic chest examination of all enlisted men that had been adopted in Germany.[11] On the basis of a crude cost-benefit calculation he advised that the savings to the military authorities of the costs of returning men, paying for their hospital treatment and subsequent pensions would be substantially greater than the costs of implementing mass radiography.

This conclusion was based on an assumption of an initial outlay of £2,500 for the scheme and a modest 1% of positive identifications amongst those examined.

He described the objective of mass radiography as a 'preliminary sorting', 'a selection of suspects who would need subsequent detailed investigation'. The method of 'sorting' could equally have been clinical examination or skin testing, but he favoured radiography because of its efficiency and cheapness in specialist time, its practicability and the availability of apparatus.

However, although it initially appeared that the 'economic savings' argument was conclusive, the question soon arose as to who precisely was to bear the costs or make the savings. Most economic costing of health care during this period was usually made without reference to transactional costs or externalities and costs were calculated on the narrow basis of departmental budgets. The organisation and funding of tuberculosis care was similar in complexity to mental health services during the inter-war years, and by 1940 was made even more labyrinthian by the general mobilisation and the involvement of the Ministry of Labour and the War Office. There were a number of departments involved that had very different interests: the Ministry of Health was responsible for civilian health; the Ministry of Labour was responsible for recruits; the services were responsible for enlisted personnel; and the Ministry of Pensions was responsible for invalided ex-service personnel.

The future costs of health care fell to different ministries depending upon the status of the person at the time of diagnosis of TB: a recruit not being enlisted was *de facto* a civilian and therefore the responsibility of the Ministry of Health; an enlisted person although invalided out was the responsibility of the Ministry of Pensions; an enlisted person prior to invaliding out was the responsibility of the Services.

Dawson in his crude calculation had fundamentally misunderstood the complexity of the issue of economic costs of screening. For if screening is about the identification of cases that will require some treatment costs, then unless there is a congruence between those departments which provide the screening service and those which provide the treatment and those which will benefit from the prevented future costs of the disease, then there is no way that an aggregation of pooled costs and benefits will be accepted in the real political world of departmental budgeting unless elaborate transfer payments are worked out.

The branches of the military had their own clinical examination schemes for enlisted persons. However, the military had an incentive to under-diagnose, since although they stood to lose manpower, the long-term costs of treatment fell not to them but to the Ministry of Pensions; so they could afford to gamble on men's future health risks. There was a natural reluctance on their part to admit that their procedures were inadequate and that they failed to pick up a substantial number of cases.

In its turn, the Ministry of Labour had an incentive to 'weed out' future costs of pensionable cases before they came on to the books of Service Entitlements. However, it was resistant to any extension of mass radiography beyond its own narrow remit of existing and called-up service personnel. It was not prepared to meet the costs for what could be seen as 'future manpower'; this being a liability it saw as falling strictly to the Ministry of Health as part of its general responsibility for the health of the country.

The primary concern of the military was to make conscription practices efficient, equitable and not subject to local variation. What was critical for them was that any testing procedure for tuberculosis should be standardised and not subject to local interpretation. They therefore had an interest in it being fully under the control of the Ministry of Labour, tied to the Recruitment Centres and operated under strictly standardised procedures.[12] From the beginning of the discussions between the War Office, the Ministry of Labour and the Ministry of Health the main focus was upon the need to have a comprehensive and standardised system that could be introduced quickly and with minimum disturbance to existing administrative procedures. Issues of logistics, standardisation of equipment and centralisation of recording systems took prominence in decision making.[13] In order for the scheme to be truly comprehensive it was deemed to be best implemented through the Recruitment Centres, but centred at specifically designated radiographic recruitment centres, the equipment was to be provided, operated and tested by the Ministry of Health. However, the Medical Advisory Committee was unclear whether the existing legal powers requiring all recruits to submit to a medical examination could be deemed also to cover a compulsory X Ray.[14] This query was never properly answered but it was decided to exclude volunteers from any compulsory requirement.

The decision that the Ministry of Health was to provide facilities, training and the whole package of mass radiography was applauded by Lord Horder as a welcome opportunity for expanding access and provision of health services and a possible entering wedge for other future development of public health.[15] The Welsh Board of Health had already established a small mobile mass radiography service for civilians and was enthusiastic about the potential for expanding it and linking it to the military scheme in Wales.[16] However, the Ministry of Labour and other voices from the Medical Advisory Committee strongly resisted any expansion of mass radiography to cover civilians, workers or students on the grounds of its expense, fears that it might interfere with war effort in the factories and concern about its effect on morale; 'people should not be troubled today by having their attention concentrated on potential ills'.[17]

This was an echo of the sceptical attitude towards presymptomatic tuberculosis that had been common in Britain in the 1930s. Journals and newspapers of the time contained long and often ironic discussions about the notion of 'pre-tuberculosis' and a dismissive attitude towards the French policy of establishing 'preventoriums' was common. There was a suspicion that the concepts of the 'delicate child' and the 'pre-tubercular child' were inventions of tuberculosis officers faced with a declining client group.[18]

By contrast the Lindsay Committee in its MRC Report on mass radiography wholeheartedly endorsed an expansion of mass radiography (M/R) to the whole population, under a rigorous and centrally controlled system operated by the Ministry of Health and linked to the local authority tuberculosis services.[19] Although local authorities might administer a future scheme, it was envisaged that the central Ministry would retain overall control over target groups, systems of record keeping and all data analysis, the design and deployment of apparatus and the precise terms and conditions of staffing of the facility. The difficult question of defining the status of M/R within traditional medical practice was handled by emphasising that it was 'not diagnosis but the *sifting* out from a number of apparently normal persons those whose condition requires further diagnosis by established methods'.[20]

By 1948 the issue of M/R became dominated by consideration of the Sickness Benefit system introduced to replace Sanatorium Benefit and to be administered by local tuberculosis officers for all new cases. The financial consequences of an increase in positive diagnosis of tuberculosis shifted to the Central Exchequer for benefit payments and to the county councils in their responsibility for providing treatment. In 1948 the Regional Hospital Boards took over responsibility for the planning and financing of tuberculosis services and thereby the Ministry of Health picked up the bulk of all treatment costs as well as responsibility for control and planning. It was clear that early diagnosis of tuberculosis through M/R might lead to benefit claims and thereby incur opposition from the Treasury; however, if cases could be diagnosed early enough, it would not involve the Ministry of Health in any greater costs in actual treatment provision. Mass radiography was enthusiastically defended and promoted by the Ministry as a common service for the country as a whole under the central control of the Ministry and by 1949 the Chief Medical Officer was arguing for an expansion of its tuberculosis focus to cover other cardiovascular and respiratory diseases, and characterising its function as 'screening'.[21]

There are a number of seams which may have contributed to the expansion of medical screening in the post-war years throughout western Europe. There was the obvious link between the war-time medical inspection of recruits and the continuity of military medicine as conscription remained and demobilisation was only slowly implemented. Here the experience of the 1914–18 war and the problems of demobilisation, displaced populations, impoverishment and chronic malnutrition of civilians created a realistic attitude towards the need for co-ordinated public health programmes to prevent epidemics and long-term destabilisation. Anti-tuberculosis work was a priority with most European Red Cross Societies and although the Health Committee of the League of Nations had been dissolved, it was quickly reconstituted as the new organisational shell of the WHO and its co-ordinated work on tuberculosis control in Europe was revived in the late 1940s.

American influence on international public health during the inter-war years, through the sponsorship of the Rockefeller Foundation and the American Red Cross, reinforced a medical model of community health (Kniebler, 1979, Lert, 1982, Towers, 1987). The Rockefeller mission to France in 1919 had pioneered an anti-tuberculosis campaign based upon mobile health education teams with their motorised caravans and film shows that bore a striking resemblance to the promotional fanfares organised for mobile mass radiographic screening units.

At the level of ideas, the 1920s had witnessed a steady coupling of the 'scientific' claims of medical procedures to legitimate state regulatory activities in the fields of family policy, deviance and criminal justice (Donzelot, 1979, Foucault, 1977, Pfohl, 1985). One can see the legitimation of medical intervention through the increasing involvement of medical professionals in a broader range of social policy making and also in the expansion of the domain of medical work, both by the creation of new fields and the adoption and transformation of others (Conrad and Schneider, 1980). Screening would seem to be one such area where there was a consolidation of existing monitoring and surveillance work in the specific field of tuberculosis coupled to a more general mandate to expand into new areas to be deemed 'health work'.

Ante-natal VD screening

The emergence of preventive VD policies in Britain is a long and turbulent story involving conflicts between the Ministry, the Army Medical Corps, the British Medical Association (BMA) and a number of pressure groups (Towers, 1980). The most prominent and vocal group was the National Committee for Combating Venereal Disease (NCCVD), later renamed the British Council of Social Hygiene, under the leadership of Mrs Neville Rolfe who has become characterised as an 'ogre' figure of lampoon in the received history of the Ministry of Health and similarly stereotyped by modern historians.

In 1951 the question was put to the Ministry of Health whether VD testing should be made routine in all pregnancy tests.[22] A policy ruling was sought in the context of the emerging reorganisation of the Laboratory Services. The working practice had been that Kahn tests were done as a matter of course by the Blood Transfusion Centre on specimens of blood from women attending local authority ante-natal clinics who were being routinely tested for Rh-factor. If a woman was found Rh-negative she would be tested at all subsequent pregnancies, but if positive she would not be tested again. The VD test was simply an added-on test, and the Blood Transfusion Laboratory, not being a Public Health Laboratory, was not prepared to take blood specifically to be tested for VD and produce separate VD data.

A lobby from the British Council of Social Hygiene, supported by one from the National Society for the Prevention of Cruelty to Children (NSPCC) led by the head of the Great Ormond Street laboratory, urged the Ministry to deal with what they claimed was an alarming increase in the incidence of congenital syphilis. They argued for a campaign based upon two measures; routine ante-natal VD testing and compulsory treatment of children with congenital syphilis.[23]

In a departmental position paper, Ministry officials saw the key issues as whether VD testing should be routine, discretionary or compulsory, and where it should be done. They needed evidence to make an assessment of whether there was even a need for it, but found themselves caught in the dilemma of how to get the information without breaching the confidentiality of the Blood Transfusion Service (BTS) and linking data sets. The British Council of Social Hygiene argued that routine ante-natal tests would provide just such an information source on venereal disease and its control; they made a strong case for its epidemiological and service monitoring potential. The compulsory treatment initiative was made on the economic grounds that congenital syphilis was not being treated and was generating future health care costs. The change proposed was for an administrative order covering the removal of secrecy and confidentiality in the VD regulations in cases of children. Venereal Disease Officers could then be empowered to give evidence to magistrates and parents could be prosecuted for failure to ensure treatment of their children. There was strong resistance to any compulsory treatment legislation, or even threat of it, from the School Medical Service and the new clinics who saw it as threatening to undermine the whole basis of their work with parents and children.[24]

On both issues Ministry of Health documents reveal a solid line of resistance to any form of compulsion and a commitment to the encouragement of service use. The question of confidentiality was positioned as a central factor to be safeguarded throughout their deliberations and although it finally overruled considerations of the needs for epidemiological data, a disquieting dodge was mooted. The possibility was explored of getting the Blood Transfusion Laboratories to pass details of cases testing positive on to the local Medical Officer of Health; this was rejected because of the likely complaints it would provoke from GPs concerned about their patients' confidentiality.[25] The laboratories continued to produce figures for the Ministry based on the old pattern of testing and the Ministry settled for the limited data on the incidence of VD in the general population of pregnant women.

VD testing as a specific part of the diagnosis/treatment VD Service was becoming repositioned as part of the newer practice of monitoring the level of VD infection in the general population. There was a convergence of interests between the British Council of Social Hygiene (BCSH) which was concerned to preserve the invincibility of the threat of VD and its own jurisdiction over the defending crusade and the straightforward interest that the epidemiologists had in securing a regular and convenient sample base. It is a nice example of the different language of legitimation which different occupational groups might use in defending a particular test as 'compulsory' or 'added-on'. It is also noteworthy that this was by definition a gender specific group and it cannot have been completely forgotten that there was a long history of viewing women as the 'reservoirs of infection' in venereal disease.

Paternity testing

This area reflects a link with the role of paediatricians in lobbying for an occupational monopoly of medical inspections in adoptive cases and the function of the Blood Transfusion Laboratories. The question of whose domain they fell within was first raised in 1948 by the Welsh Hospital Board.[26] The National Blood Transfusion Service (NBTS) did not want to handle blood testing for the purpose of affiliation proceedings. The Ministry of Health was similarly concerned about NBTS Officers giving evidence in court and thereby raising suspicions about the confidentiality and professionalism of the whole blood donation scheme.

Affiliation proceedings fell under the auspices of the Home Office but since blood testing was not specifically required under legislation on Bastardy, it disclaimed any responsibility for making arrangements for its availability. The Ministry of Health estimated that although there was a demand of 2,000 tests per year in England alone, they were not prepared to simply extend laboratory facilities to cover this new area of work which smacked of forensic pathology. This was a good example of the Ministry of Health refusing to yield to the Home Office strategy of 'hand washing', and to the potential to expand 'health work' in directions they saw as undesirable for their ethos. It was the university laboratories which eventually picked up this work on a private fee for service basis.

This particular issue raised a lot of opposition from pathologists who saw it as further evidence of the declining status of laboratory work and the undermining of their occupational monopoly and professional credibility by the commercial laboratories. The Ministry of Health files record a deep loathing of what they referred to as the 'shop model' of laboratory work; one such example can be found in a position paper on the private laboratories written in 1949:

> no-one who knows the facts doubts the evil influence they have exerted on medicine as a whole. They are in no sense an important or useful industry and the sooner they are put out of business the better. The universities case is not much stronger – in many perhaps most universities, the earnings of fees for routine diagnostic work has reacted very badly on the pathology and bacteriology departments concerned.[27]

The distinction between medical work and technical laboratory work raises issues about the nature of expert knowledge that become more complex when such work is positioned in a forensic context as can be seen in the recent use and development of DNA fingerprinting which have been confined to the commercial sector in Britain. The new work being done on the social construction of forensic knowledge needs contributions from historians of such antecedents (Smith and Wynne, 1989).

The medical inspection of aliens

Since the 1920s the medical inspection of aliens had been the responsibility of Port Medical Officers. The Home Office was responsible for immigration but the Ministry of Health had a key role in the granting or withholding of medical certificates. The significance of this role was raised in 1947 during the period of increased immigration through post-war resettlement and manpower schemes. This issue of medical involvement with immigration policy came at the same time as other cases were being considered in which health services were being reformulated and a number of different Ministries were negotiating their jurisdiction over health work.

The issue was first publicly raised by the xenophobic concern that foreigners were coming into the country with Home Office approval but became sick and were a 'drain' upon local authority health services. Concerned rate payers wanted to know whose responsibility it was to make sure it did not happen.

The Ministry of Health saw it as a matter of medical inspection at ports of entry being grossly inadequate. However, if it was made adequate then delays and complex arrangements for 'holding' immigrants would have had to be made and it was feared that this would attract political attention and result in a possible retaliatory action by other countries against Britain.[28]

The problem for the Ministry of Health was that even if the Medical Inspectors of Aliens (MIAs) could effect satisfactory examinations the immigration officers had the power to overrule them. Here was a clear confusion about the primary function of immigration control.

There was great variation in what a medical examination entailed, despite the confidential and specific guidelines issued by the Ministry of Health and its characterisation as an 'examination'. There were two elements:

1. A visual examination. (In practice this meant giving the queue on the disembarkation plank a once over.)
2. A thirty-second examination of selected passengers in a set-aside corner of the exit hall.

What the MIAs were having to decide in this inspection was primarily whether the immigrant was suffering from a current infectious disease or was likely to become a dependent on state health services. There was a gross confusion between social and medical issues on which the MIA was called to adjudicate and yet was not provided with such critical information as age, marital status or occupational category.[29]

Reviewing the whole policy objectives of the medical inspection of aliens in light of the new National Health Service structure, the Ministry concluded that its function was to prevent any increase in the burden of demand on health care resources. This it was assumed was likely to be heaviest in cases of chronic disease and yet it was virtually impossible to identify these cases in the sort of medical inspection possible in thirty seconds in a busy landing concourse.[30]

The Home Office had no specific interest in preventing long-term health care demand, but was concerned to prevent confusion in issuing entry permits and to minimise deportations. It made a primary distinction regardless of health status between those who stated they were prepared to seek private health care and those who were not. The MIAs refused to accept the responsibility of having to ascertain the motives and reliability of such statements.

Conflict between the Home Office and the Ministry of Health continued and the vexed question of the purpose of inspection was raised regularly throughout the 1950s. The service continued to be subject to low morale, sudden flare-ups, panics and chronic delays.

Connections and issues

Out of these brief sketches I should like to draw out one or two simple connections. There is not the space to give detailed systematic attention to a full range and I have traded off the benefits of depth and detail against the wish to raise discussion points that come out of not just this research but hopefully pertain to the broader range of material covered in the book. The background thematic considerations are the related issues of what is meant by 'knowing' and what are the associated costs and benefits of knowing.

In the field of TB work there was a long inter-war history, both nationally and internationally, of trying to discover what was the 'real' epidemiological picture of this disease. Attempts to establish an international clearing house at the League of Nations of a whole range of epidemiological data collected by nation states was fiercely contested. The British government feared that although it was a desirable plan, those countries with the most developed and bureaucratised health care systems would produce artefactually high rates of TB mortality and morbidity. When the International Classification of Diseases (ICD) standard was introduced in a patient record system for panel doctors in 1921 it was vehemently attacked by the *Times* newspaper as part of the Ministry of Health's craving for useless but sonorous statistics and it was claimed that overworked doctors would simply compound their clinical ignorance with the production of unreliable data. It was argued that the record system, by forcing doctors to name diseases such as TB, rather than simply record general observations, would generate political problems: 'the new record cards . . . tell us nothing but untruths, untruths will go to Whitehall and be bound in blue covers. We shall learn anew that we are the least healthy nation in Europe or the world and great and costly schemes of regeneration will be submitted to Parliament.'[31]

I am sympathetic to a constructionist view of the production of epidemiological knowledge and would start from a position that sees the production of any statistical knowledge as a labour process in which a number of occupational groups are involved, whose interests and claims are often in conflict (Whiston, 1979). Existence of this in Britain is found in the number of detailed complaints made to the Ministry of Health from the Joint TB Council, panel doctors, medical officers of health and tuberculosis officers. General practitioners objected to compulsory notification of a disease, which they saw as an attempt to trespass upon their relationship with their patients and further placed them in a subservient position to the public health departments. Tuberculosis officers complained that the amount of administrative and statistical work they had to do encroached upon their time to do clinical work and reinforced their low status within the medical profession. In a context of much distrust, low levels of co-operation, lack of administrative support and a general climate of resistance to the authority of central government departments, which were seen as remote, coercive and regulating centres of power, it is not surprising that the quality of data was variable. There is a fundamental difference between record keeping as an administrative function and using the records for research purposes; the data may give a good picture of organisational reality but they should not be mistaken for a picture of the social distribution of tuberculosis. This is a familiar difficulty facing any researcher using government health statistics in any field; namely that the state is in the business of collecting data not on social conditions but rather data on the operation of its agencies responsible for dealing with them and that inevitably the categories and units of analysis are grounded on particular theoretical assumptions and are not objective technical instruments.

Before mass radiographic screening, data on tuberculosis were generated primarily through the clinical diagnosis of the individual presenting patient. The major problem was that one of the characteristics of pulmonary TB is that as a disease it usually is presented with symptoms, however, that is not always the case and many people, even with extensive disease had symptoms which they ignored or interpreted within a social rather than a medical diagnostic typology and some patients were truly asymptomatic. However tight the diagnostic categories and descriptions might have been drawn, diagnosis was a practical activity undertaken with an individual patient and was not only a matter of judgement but often a highly subjective judgement. Mildred Blaxter (1978) has suggested when diagnosis as a category gets out of step with diagnosis as a process then the result may be arbitrary choice of label and perhaps inappropriate action. In the case of TB, positive diagnosis had implications of compulsory notification and a therapeutic action based on institutional treatment, both of which had severe consequences for the patient in terms of stigma and loss of earning capacity which could not be compensated for by any confident prognosis of future recovery.

How far was this element of subjectivity removed by the development of laboratory tests and X Rays? Shyrock (1961) has demonstrated in the case of Wassermann tests for VD that subjective elements lurk behind a facade of statistical and quantitative exactitude; and Reisler (1978b) has analysed the reality of laboratory work where contaminants, random variations, human errors, the profitability ethic and the speed of the work process structure the production of 'knowledge'. Radiologists since the 1920s have cautioned against an unquestioning acceptance of their readings, pointing out that sensory acuity is related to the context and amount of film reading that is done (Lynham, 1925).

My own tentative conclusion is that the knowledge produced by these screening procedures was of the same order as before. It tells us about the social operation of the service provided but it must not be confused with the rhetoric of legitimation of 'scientific truth' that it was given. This knowledge was evaluated by different interested parties according to partial, selective and instrumental criteria. In the case of the medical inspection of aliens, the visual examination and interviews failed to pick up on the most basic exclusionary categories of VD, TB, mental infirmity, pregnancy and epilepsy, all of which were likely to result in future health care demand. But without health economists to provide calculations based on pro-rata treatment costs, or even 'future productive life years', the Home Office settled for the cursory inspection and subjective interviewing as a system which generated the least political and administrative disbenefits. At the same time the medical practitioners were able to retain a territorial domain within the field of immigration control, despite the erosion of its clinical legitimacy. This example would suggest that the ability to retain a contested knowledge field in the face of its declining internal validity is related to occupational and class power and is in line with an externalist view of the history of medicine.

An internalist history of testing and screening would look to developments within the medical technology as a record of increasing scientific accuracy. This raises the question of what could be characterised as an 'engineering' versus a 'managerial' view of accuracy. The first is based upon principles of scientific validation, the second upon the notion of optimisation. In these stories of screening this is reflected in the overt recognition by policy makers that the reliability of the procedures was to be appraised on the bases of the economic consequences or outcomes of the results. A false clear medical certification was a problem for the Home Office if subsequent health care costs were generated by a landed immigrant if deportation on health grounds was not permitted. False positives in VD testing had significance for doctors and patients if the network of follow-up services was involved, but if it was a general surveillance exercise then this could be allowed for within margin errors. The issue of false negatives was of limited importance in paternity testing since the test result could only be used to exclude paternity – i.e. as negative evidence in affiliation procedures. It was generally recognised that the consequences of this meant that the forensic nature of the test was only part of the legal case and a false negative bias fitted more easily within the legal presumption of innocence and an adversarial approach to use of forensic evidence (Fortess and Kapp, 1985).

Calculations of economic costs during this period were crude and it is probably not surprising that patients' costs were generally not considered. The costs of stigma and anxiety to patients from false positive results in both mass radiography and VD testing were only considered in terms of the impact upon future service utilisation. The devastating personal costs borne by aliens deported on the basis of the cursory medical examination were never considered unless they reached the open forum of Parliament and became a subject of special political interest.

Here we can see the thread of the issue of confidentiality. It was generally believed that whilst in the case of TB, the consequences of treatment coupled with insurance entitlement would not be detrimental in the case of false positive diagnosis, nevertheless the stigma caused by the loss of confidentiality, which hospitalisation and notification would entail, was significant. Employers' costs in lost production were given due weight and reimbursed. It was even seriously considered in the Ministry of Health that employers who provided site facilities and time off to attend M/R might be entitled to know the results of any of their own participating employees.[32]

The question being touched upon is how far confidentiality of medical information is to be seen in strict terms of the doctor/patient dyad or whether there is an inevitable interconnectedness of wider medical practices which necessitate shared information. Debates about the confidentiality of information in modern bureaucratic states are usually centred around the control of access to that information and the licensing or empowering of groups to gain access. Administrative efficiency in the case of ante-natal VD testing was found to override the confidentiality of the clinic but it was regarded as defensible provided the circulation of information was only within professional groups. Here it was the medical statisticians, the Blood Transfusion Laboratories and the Ante-Natal Clinic who were designated as 'fit persons' to share data which could still be regarded as confidential.

The matter of where the boundaries of information sharing are drawn must in part be connected with the further implications of managerial action that interested parties have. If employers are to be given information on their employees in a voluntary, state-funded scheme to which they also make additional contributory expenditure, do they have greater claims and how does this situation differ from employer-organised schemes in which a condition of employment is mandatory screening? The new developments of occupational screening for conditions which might give rise to sickness claims or have an impact on the health and safety of production raise just such questions, particularly in the USA where employer-financed health insurance is extensive. Occupational genetic testing for conditions with a prognosis of long-term disability and dependency will compound the debate further.[33] In an indirect way this whole matter was considered in the discussions between the Home Office and the BMA in 1958 over the development of medical screening of adoptive parents, with a view to weeding out those putative parents whose life expectancy and health status would prevent them from being financially responsible for the adopted child before the age of maturity.[34] The Home Office regarded such medical information as clearly their own property to be shared with appointed probation officers, and sometimes had a reluctance even to allow it to be shared with the adoptive parents themselves.

It is apparent that even the decisions to ascribe confidential status to information on people is contingent upon the status of the person in question. Despite enthusiastic weeding of PRO files, detailed medical records of named aliens are openly available. As a researcher I am caught between a desire to gain access to material and a disquiet about the selective availability of it and the privilege of access which is differentially allocated.

Although the screening procedures discussed in this paper have been situated in a medical domain and legitimised as aspects of a preventive health policy, they can also be seen as a set of activities that are open to critical review when they are operated outside of the medical domain and legitimised by commercial criteria. When insurance companies are found to be using HIV tests for actuarial purposes, they may be indicted but in the light of historical practice by what criteria could this be called an immoral form of medical screening? Insurance companies now, just like the Ministries of Defence and Labour then, face real potential costs. In the past they have screened for opiate addiction and TB and in the future, with genetic screening and the much greater emphasis on health checks, they may well screen for a whole variety of conditions. Looking back in fifty years' time it may well be that it is the last few decades in which they have made very few exclusions that seem historically odd.

Acknowledgements

I should like to thank Rudolf Klein for his encouragement of my interest in screening, and Marilyn Lawrence and David Painting for their sustaining help in the production of this paper.

NOTES

1 A point made by Daniel Fox, discussant at Aids and Contemporary History Conference, 1990, London School of Hygiene and Tropical Medicine.

2 PRO MH55/1256, 8 Oct. 1942, Report of Advisory Committee on Tuberculosis, Mass Radiography Subcommittee (chairman: Lindsay).

3 PRO MH55/1264, Feb. 1940, memo from Dawson to McNalty.

4 PRO MH55/1262, 1942, Report of Mass Radiography Subcommittee of MRC.

5 PRO MH55/1269, 1954, memo from Ainsworth to Chief Medical Office.

6 PRO MH55/1067, 1941, Report of Medical Committee of Welsh Board of Health.

7 PRO MH55/1269, Nov. 1947, memo Alex Hoad.

8 PRO MH55/1525, 1953, memo McElligott.

9 PRO MH55/1658, 1949, memo Dr Maurant.

10 The British position, put by Major Greenwood, the Chief Statistician at the MRC was extensively discussed in the *Bulletin of the Health Organisation of the League of Nations* (1932). Greenwood wanted a rigorous analysis of Calmette's work since the MRC had some vaccine and would not proceed until a strong *prima facie* case could be established for its reliability or otherwise, it was claimed, it might be seen as an experiment on human beings. But others have argued that Greenwood delivered a devastating statistical attack on Calmette's work and, whilst his conclusions were justified, it had the effect of throwing the baby out with the bath water and no constructive contribution to the BCG programme came from Britain for the next twenty-five years. (P. D'Arcy Hart, 'Efficacy and applicability of mass TB vaccination in TB control', *British Medical Journal*, 1 (1967), 587.)

11 PRO MH55/1264, Feb. 1940, memo from Dawson to McNalty.

12 PRO MH55/1264, May 1940, memo from Medical Advisory Committee to McNalty on Administrative, Financial and Legal Aspects of Mass Radiography.

13 PRO MH55/1264, note on reactions of Admiralty, War Office and Ministry of Labour to Dawson memo.

14 PRO MH55/1264, May 1940, memo from Medical Advisory Committee on Administrative, Financial and Legal Aspects.

15 PRO MH55/1264, 5 Feb. 1941, memo from National Conference of Friendly Societies.

16 PRO MH55/1067, 1941, Report of Medical Committee of Welsh Board of Health.

17 PRO MH55/1067, 19 Sept. 1941, letter from Robinson to Glynn Jones of Welsh Hospital Board (WHB).

18 It was acknowledged that there was no firm medical basis for this diagnostic category; it was, however, widely used by those in the TB Service to select children for particular educational and welfare attention. A. S. MacGregor, Medical Officer of Health (MOH) for Glasgow admitted in 1931 that 'administrative provision has followed the view of clinicians very closely, often up dubious paths and blind alleys. We can remember the days when in search of the early case upon whom to exercise preventive measures, the pre tuberculosis child received extremely prominent treatment . . . it now appears that the pre tuberculosis child is something of an abstraction' (Transactions of the TB Society of Scotland, 1930–1). In Britain these children were usually those who were on the books of the dispensary in the 'under observation' category; however, public health administrators were loathe to let them remain there for any length of time since the category would become unwieldy. By recategorising them as 'delicate' the children became eligible for help by the School Medical Service with access to open air schools and food supplements. Whilst the category of 'delicate child' was recognised by the Educational Service it was derided by Tuberculosis Officers (TOs) as 'vague'. This group of 'delicate' children was a strange category of illnesses and behaviours, including 'weak lung', 'stammerers', 'asthmatics', 'chronic eye infections', 'anaemia'. They were the forerunners of the 'maladjusted' child who sat at the borderline of the medical diagnostic categories and ones being developed by the new occupational groups (social workers and child psychologists) involved in child care.

19 PRO MH55/1256, 8 Oct. 1942, Report of Advisory Committee on Tuberculosis, Mass Radiography Subcommittee (chairman: Lindsay).

20 PRO MH55/1262, 1942, Report of Mass Radiography Subcommittee of MRC.

21 PRO MH55/1269, 1949, memo from Ainsworth to Chief Medical Office.

22 PRO MH55/1525, 28 Nov. 1951, Position Paper on Syphilis Testing in Pregnancy.

23 PRO MH55/1329, 13 Aug. 1941, memo from British Social Hygiene Council (BSHC) on Routine Ante Natal Test for Syphilis.

24 First raised in PRO MH55/274, Congenital Syphilis in Children, memo from McNalty, 10 Nov. 1932.

25 PRO MH55/1525, 28 Nov. 1951, Position Paper on Syphilis Testing in Pregnancy.

26 PRO MH55/1658, 16 March 1948, letter from National Blood Transfusion Service to Welsh Board of Health.

27 PRO MH55/2146, 1949, memo on possible schemes of Hospital and Public Health Laboratory Service.

28 PRO MH55/1885, June 1949, correspondence of Ministry of Health with Home Office.

29 PRO MH55/1885, 1951, Account of Medical Inspection of Aliens, Harwich: 'I cannot help feeling a thirty second medical examination is really of little value'.

30 PRO MH55/1885, June 1949, letter from Ministry of Health to Home Office.

31 *Times*, 5 Jan. 1921.

32 PRO MH55/1256, 1943, memo on Records.

33 This was extensively discussed at the conference on 'Biological Monitoring and Genetic Screening in the Industrial Workplace', Washington, May 1983, Report in Field 1983.

34 PRO BN 29/39, 1958, Discussion Papers on Childrens Act, Medical Certificate.

REFERENCES

Barlowe Report, 1919 HMSO Cmnd 31.

Blaxter, M., 1978 'Diagnosis as category and process: the case of alcoholism', *Social Science and Medicine*, 12: 9–17.

Conrad, P., and Schneider, J., 1980 *Deviance and Medicalization*, St Louis.

Donzelot, J., 1979 *The Policing of Families*, London.

Field, R. I., 1983 'Biological monitoring and genetic screening in the industrial workplace: a synopsis and analysis', *Law, Medicine and Health Care*, June: 125–9.

Foltz, A. M., and Kelsey, J. L., 1978 'The annual pap test: a dubious policy success', *Millbank Memorial Quarterly*, 56, 4: 426–62.

Fortess, E., and Kapp, M., 1985 'Medical uncertainty, diagnostic testing and legal liability', *Law, Medicine and Health Care*: 213–17.

Foucault, M., 1977 *Discipline and Punish: The Birth of the Prison*, London.

Howard-Jones, N., 1978 *International Public Health between the Two World Wars*, WHO, Geneva.

Kniebler, Y., 1979 '"La lutte anti tuberculose". Instrument de la medicalisation des classes populaires 1870–1930', *Annales Bretagne et des Payes de l'Ouest*, 86.

Lert, F., 1982 'Emergence et devenir du systeme de prise en charge de la tuberculose en France entre 1900 et 1940', *Social Science and Medicine*, 16: 2073–82.

Lynham, J. E., 1925 'The use of X Rays in the diagnosis of pulmonary TB', *Tubercle*, June.

MacGregor, A. S., 1931 'The TB schemes, administrators and clinicians', *Transactions of the TB Society of Scotland* (1930–1).

Pfohl, S., 1985 *Images of Deviance and Social Control: A Sociological History*, New York.

Reisler, S. J., 1978a 'The emergence of the concept of screening', *Millbank Memorial Quarterly*, 56, 4: 403–25.

1978b *Medicine and the Reign of Technology*, Cambridge.

Shyrock, R. H., 1961 'A history of quantification in medical science', *ISIS*, 5, 2.

Smith, R., and Wynne, B., 1989 *Expert Evidence: Interpreting Science in the Law*, London.

Towers, B., 1980 'Health education policy 1916–26: venereal disease and the prophylaxis dilemma', *Medical History*, 24: 70–87.

1987 'The politics of tuberculosis in western Europe 1914–40', unpublished dissertation, University of London.

Whiston, T., 1979 *The Uses and Abuses of Forecasting*, London.

4

Testing for a sexually transmissible disease, 1907–1970: the history of the Wassermann reaction

ILANA LÖWY

Introduction: *Genesis and Development of a Scientific Fact* revisited

'If one wants to study scientific facts', explained the bacteriologist and philosopher of science Ludwik Fleck in 1935 in the introduction of his book *Genesis and Development of a Scientific Fact* – today viewed as a pioneering study in the sociology of scientific knowledge – 'a medical fact, the importance and applicability of which cannot be denied, is particularly suitable, because it also appears to be very rewarding historically and phenomenologically. I have therefore selected one of the best established medical facts: the fact that the so-called Wassermann reaction is related to syphilis.'[1]

Fleck's choice of the Wassermann reaction was motivated by two reasons. One was the central role of this test in the development and the present structure of his own scientific specialty – serology. The other was the observation that the most famous serological reaction was based on the use of a non-specific antigen and was thus squarely in contradiction with fundamental principles of immunology and serology.[2] These principles had been summed up in 1910 by Wassermann's collaborator Julius Citron. The fundamental law of immunology, Citron explained, is that 'every true antibody is specific and that all nonspecific substances are not antibodies. The law of specificity is the precondition of immunodiagnostic.'[3] This particularity of the Wassermann reaction was central to Fleck's argument that additional, sociologically based explanations are needed to account for the genesis and rapid diffusion of this test.

The discovery that the Wassermann test is in contradiction with the theoretical principles of serodiagnostic did not diminish the practical impact of this test. Just the opposite was true: in the years following the publication of Wassermann's original paper, the test attracted considerable interest on the part of scientists and physicians. It was perfected through a sustained effort of numerous individual investigators, then standardised in a series of international conferences and meetings. The relation of the Wassermann reaction to syphilis, Fleck claimed, could become a generally accepted 'scientific fact' only through the collective activity of the appropriate scientific community. But how was this activity possible in the first place? Why did scientists obstinately look for a blood test for syphilis, all technical and conceptual obstacles notwithstanding? Fleck's answer is that the Wassermann reaction was made possible on the one hand by the persistence of the ancient belief in the existence of tainted 'syphilitic blood', and on the other because of the great fear of syphilis and its consequence, by the priority given by the public authorities to research on this disease. The conjunction of these two factors stimulated the collective effort to search for a blood test for the detection of syphilis, overcame the obstacle of scientific uncertainty and allowed the elaboration of a highly efficient test for the detection of this disease. Fleck believed also that lack of understanding of theoretical principles of the Wassermann reaction had led to the development of tests based solely on complex technical considerations, and, in consequence, to the confinement of syphilis testing to a narrow, esoteric circle of specialists: the serologists. The community of serologists developed unusually dense internal links, but at the same time isolated itself from other scientific disciplines and from the exoteric circles of biologists, general practitioners and the lay public.[4]

In his pioneering work Fleck made explicit the mechanism and the consequences of social construction of what he believed to be an uncontestable 'medical fact'. In all probability even such an unorthodox critic of science as Fleck did not suspect that the Wassermann test, the basis of compulsory premarital screening, was far from being well established as a 'medical fact' as it was believed in the 1920s and 30s. In this paper I will deal with the metamorphoses of the 'medical fact' studied by Fleck, and use this example to illustrate the difficulties of application of 'scientific facts' to medical practice. In the first part, I will describe the 'genesis and development' of the Wassermann test and of other tests based on similar principles in the years 1906–40, then, in the second part, I will follow the radical modifications in the interpretation of 'non-treponemal' tests for syphilis after the Second World War and their practical consequences. Finally, in the conclusion, I will consider the relevance of the history of syphilis testing for a contemporary problem: AIDS testing.

The Wassermann test: the 'genesis and development' phase

The puzzle of the Wassermann reaction

The discovery of the etiological agent of syphilis, Treponema pallidum, by Schaudinn (1905)[5] allowed in some cases (e.g. primary syphilitic lesions) for a direct diagnosis of syphilis. It also confirmed the possibility of developing a blood test for this disease. Wassermann and his collaborators, Neisser and Bruck, assumed that a syphilitic patient would carry in his/her blood specific anti-treponema antibodies. It was difficult, however, to demonstrate directly the presence of such antibodies because it was impossible to grow Treponema pallidum in a test tube. They attempted therefore to use the indirect method of complement fixation, developed by Bordet and Gengau in 1901,[6] which reveals the presence of specific antibodies in the blood of an infected individual. The complement fixation test is based on the principle that when antibody-containing serum is allowed to react with a specific antigen (in the case of the Wassermann test, an extract of a syphilitic liver, rich in treponema antigens), in the presence of guinea-pig complement, the complement will be absorbed by the antigen–antibody complexes. This disappearance of the complement from the reaction mixture can then be demonstrated by a revealing system. In their first publication, Wassermann, Neisser and Bruck[7] affirmed that about 80% of syphilitic sera – but no normal sera – reacted with an extract of syphilic liver. The new test was rapidly used to strengthen the strongly suspected (but, in 1907, not yet proven) etiological links between the primary Treponema pallidum infection and late clinical manifestations such as tabes and dementia paralityca.

When Wassermann and his collaborators described their test, they assumed automatically that it was a specific reaction, closely related to other tests of complement fixation mediated by specific antibodies. Soon, however, it was found that the reaction was in all probability a non-specific one: sera from syphilitic patients reacted also with extracts of organs from normal individuals. At first attempts were made to minimalise the importance of reactions with normal tissues.[8] However, in the years 1907–8, several studies independently confirmed that the Wassermann test might be made with extracts (in particular alcoholic extracts) of normal tissues. Those results put an end to the discussion on the immunological specificity of the 'Wassermann antibody' (called 'reagin', in order to distinguish it from classical antibodies) and opened a debate on the chemical nature of the substances which react in this test and on their relationships to pathological phenomena induced by Treponema pallidum.[9] The theoretical and practical questions were rapidly dissociated. While the elucidation of the biochemical nature of the substance(s) reactive in the Wassermann test and the understanding of the pathological process underlying this reaction was slow to come, physicians and serologists rapidly consolidated the links between Wassermann reaction and treponemal infection, and perfected the technical aspects of this test.

In 1909, it was largely accepted that a positive Wassermann reaction is the result of the 'modification of the colloid properties of the serum'. Such modification, usually viewed as a quantitative and not a qualitative one, was somehow related to the presence of an active pathological process. It was found that, unlike the 'classical' antibodies which usually persist in the serum long after the disappearance of an infection, the presence of 'reagins' is often correlated with the presence of an active disease, and they tend to disappear from the serum after a successful anti-syphilitic treatment. Some authors explained that the

'Wassermann reagins' were decomposition products of tissular origin which appear in the serum as a result of the destructive action of the treponema upon the host tissue.[10] Other investigators believed that the treponemal infection somehow modified the equilibrium between the colloids of the serum and/or alternated their physico-chemical properties.[11] Finally, it was postulated that the reagins are auto-immune antibodies ('auto-cytotoxins') directed against the host's tissues.[12]

Early chemical studies of 'Wassermann reagins' and the lipoid 'antigens' with which they react failed to elucidate the link between the 'colloidal modification of the serum' and the pathological processes in primary, secondary and tertiary syphilis.[13] This was not surprising. In the 1910s and 20s the chemical nature of 'classical' specific antibodies was not much better understood than those of 'Wassermann reagins', allowing for the claim that 'classical' immunological reactions are, like the Wassermann reaction, based on unspecified 'colloidal modifications' of the serum.[14] These studies allowed, however, the perfection of the Wassermann test through optimisation of the 'antigen' source (usually, alcoholic extract of beef heart mixed with lecithin) and detailed codification of the technical aspects of the reaction.[15]

In the late 1930s the development of a new technology – ultracentrifugation – led to a demonstration that antibodies are not, as Fleck believed, names given to symbolic properties of the serum, but are well-defined chemical molecules, the immunoglobulins. At the same time, a growing body of evidence pointed to a structural similarity between 'Wassermann reagins' and 'classical' antibodies.[16] The elucidation of the chemical nature of Wassermann reagins put an end to the speculations that 'reagins' were unspecified 'colloidal modifications' of the serum, or that they were decomposition products of tissues. Two non-mutually exclusive hypotheses remained: the 'reagin' is an antibody directed against a cross-reactive, non-species-specific lipoid component of the treponema, and/or it is an auto-antibody directed against a lipoid component of the host's cells.[17] The finding that reagins were *in fine* true antibodies, perhaps related to an auto-immune process, did not explain, however, why a high concentration of these antibodies appear in syphilitic serum, and what precisely their link with the pathological phenomena induced by an infection with Treponema pallidum is.

The specificity of the Wassermann test: 1906–40

The question of the relationship between the appearance of atypical 'Wassermann antibody' in the blood and the pathology of syphilis, although undoubtedly of interest to scientists, may have been viewed as relatively unimportant by clinicians. The Wassermann test and its derivative, the flocculation test,[18] had above all a practical aim: the specific diagnosis of syphilis. Before the Second World War, this goal was viewed as fully achieved. The Wassermann test, Fleck explained in 1935, demonstrated how the collective effort of the community of serologists transformed the initial doubtful results and false assumptions into an uncontestable scientific truth. Thanks to an impressive collective labour, summed up in more than 10,000 scientific papers, the specific links between Wassermann reaction and syphilis became one of the best established medical facts.[19]

But what was precisely the nature of this 'medical fact'? A serological reaction is evaluated according to its sensitivity – its ability to react in the presence of a given disease, and its specificity – its ability not to react in the absence of this disease. Ideally, a test should be both highly sensitive (i.e. yield few, if any, false negative results) and highly specific (i.e. yield few, if any, false positive results), but in real-life conditions tests usually have either higher specificity or higher sensitivity. In the years 1906–40 the Wassermann reaction was viewed as a test with limited sensitivity and high specificity. The 'scientific fact' discussed by Fleck was in all probability not only the observation that confirmed syphilitic patients have a positive Wassermann test, but that in doubtful cases a positive result of a Wassermann test indicated the presence of syphilis, and of syphilis only. This affirmation was made from the earliest period of the introduction of this test. In 1907, one of the first articles on the Wassermann reaction in the US medical press explained that 'a sure conclusion from a positive reaction seems certain. This is especially valuable in diseases in which the determination of etiologic reaction to syphilis is in question and, which, if certain, so much depends on prompt antiluetic treatment.'[20] While a negative response to the Wassermann test was considered of doubtful diagnostic value, a positive response was seen as a solid proof of active syphilis. If, in a properly executed test, 'a suspicious serum is found positive, it can be said without hesitancy that the patient has syphilis'.[21]

One of the problems with the Wassermann reaction was its technical complexity. The test was very delicate, and it was necessary to constantly verify each of the components of the reaction. The belief in the high specificity of the Wassermann reaction was always based on the assumption that the test was properly executed. On the other hand, the fact that the original Wassermann test was technically complicated made possible maintaining the faith in the specificity of the method by attributing all the inexplicable results to laboratory errors. A doubtful result of the Wassermann reaction, claimed one specialist, 'in practically every instance is traceable to a failure of controls and to improper use of materials',[22] while another affirmed that 'it is true that in certain diseases other than syphilis positive reactions have been reported, but before these can be accepted it is necessary that every possible technical error be definitively excluded'.[23] The Rockefeller Institute bacteriologist Hideyo Noguchi affirmed that studies in which a high percentage of positive results of the Wassermann test was found in patients suffering from a variety of acute and chronic diseases should not be believed: 'it should be suspected that when one obtains a high percentage of positive reactions in non-syphilitic cases one is not doing the test properly'.[24]

Aware of the technical difficulties of Wassermann reaction, Noguchi attempted to develop a simplified form of the test and the introduction of standardised reagents, dried and distributed on filter paper. Such reagents, Noguchi explained, might be prepared on a large scale by commercial biological laboratories under the supervision of a competent serologist, and might be placed on the market within the ready reach of physicians. This method (a precursor of the present 'kit' methods for antibody testing) should allow the test to be performed by any clinician who is used to making clinical laboratory tests.[25] Noguchi's colleagues strongly disagreed. The Wassermann reaction, they affirmed, is too delicate to permit its use by non-specialists. While the reaction is highly specific in the hands of expert laboratory men who know all about the principles of hemolysis, its diffusion among non-specialists would lead to a considerable increase in the occurrence of 'false positive results', the more so because the Noguchi reaction was of somewhat lower specificity than the original Wassermann test. Such 'false positive' results have potentially disastrous consequences for the patient and his family.[26] Following this debate, Noguchi accepted the principle that specific training is indispensable in order to obtain reliable results in syphilis testing. As to the lower specificity of his test, he admitted that his method might indeed produce some 'false positive results'. On the other hand this limitation of his test is compensated by its higher sensitivity, and thus its higher efficiency in cases in which the goal is not diagnosis but elimination of the possibility of infection: 'for selecting wet-nurses, recruiting for the military or naval services, choosing a donor of blood for transfusion etc., a system which will not miss the reaction whenever there is one should be recommended'.[27]

The modified Noguchi method was finally adopted by some laboratories. It is advantageous, affirmed a laboratory manual in 1914, to use simultaneously two methods, one with lower specificity (Noguchi) and another with lower sensitivity (Wassermann): 'The Noguchi method gives a positive reaction with non-syphilitic sera in about 7% of the cases. The Wassermann gives a negative result in about 9% of syphilitic sera. These figures show the advantage of checking one against the other.'[28] This statement illustrates the general agreement on the high specificity of the original Wassermann method, at least in non-tropical countries. It was found that the Wassermann reaction was positive in some tropical diseases: other treponemal infections (framboesia, yaws) leprosy and trypanosomiasis. But 'so far as the inhabitants of the temperate zones are concerned, a positive reaction practically excludes every disease but syphilis'.[29]

A consensus on syphilis testing was established around 1910. Although several technical modifications and simplifications of the test were proposed, the original (and the most complex) Wassermann method was viewed as the most trustworthy one. As a consequence, it was strongly recommended that in order to avoid false positive and false negative results, syphilis testing would be confined to specialised laboratories only. This conclusion later played an important role in the development of serology as a distinct sub-speciality of clinical bacteriology. On the other hand, if performed by competent specialists the Wassermann reaction was considered highly trustworthy, and a positive result was seen as a nearly absolute proof of syphilis, able to reveal hidden cases of this disease.[30] For example, an American physician, Dr Litterer, affirmed that the Wassermann test disclosed the high incidence of syphilis among city blacks:

> it is evident from the above that a good percentage of the city negroes have syphilis, either acquired or congenital, and do not know it, or else their statements could not be depended on concerning this affection . . . I am of the opinion that a good percentage of the city negroes of the south giving negative syphilis histories will show a positive Wassermann reaction as modified by Noguchi, since many have hereditary syphilis.[31]

Several factors contributed to the uncritical acceptance of the positive results of the Wassermann test as a proof of hidden treponema infection. One was the chronic character and proteiform manifestations of the late stages of infection by Treponema pallidum. In cases of doubtful or poorly defined pathological manifestations, syphilis was always suspected. The second factor was the widespread conviction, fuelled by the popular fear of this disease, that syphilis was highly prevalent, in particular among persons of low socio-economic status. During the Budapest Congress of Medicine of 1909, a German physician, Dr Blashko claimed that 20% of the mortality in Berlin's hospitals was due to syphilis.[32] A high percentage of positive results in the Wassermann test were viewed as a confirmation of this shared conviction. 'The specialists of syphilis have often been accused of "seeing syphilis everywhere"', explained a French specialist, Dr Leredde: 'But, it is proven today that the syphilis specialists themselves were unable to see syphilis in all the places where it really exists, and, on the other hand, that they have not sufficiently recognised its gravity . . . It is difficult to conceive the number of mistakes of which the syphilitic patients are victims.' Thus, Leredde added, the Wassermann test revealed the presence of syphilis in young women with a lupus diagnosis, and in numerous elderly patients suffering from cardiovascular or neurological disorders.[33]

The diagnosis of the syphilitic origin of a given illness was often made on the basis of a positive Wassermann reaction alone. The first rule was: if in doubt, test. The physician should never give credence to the patient's affirmations that he had never had syphilis, and 'in each case of an individual presenting doubtful symptoms, even if syphilis seems highly improbable, one should apply the sero-reaction'.[34] The second rule was: if the Wassermann test is positive, start immediately an anti-syphilitic treatment. The positive Wassermann reaction, viewed as a highly trustworthy indication of active syphilis, became a central diagnostic element in affections of unknown etiology, and 'energetic treatment should be commenced at once after a positive reaction has been obtained in every case, without waiting for the development of further symptoms'.[35] And, one should remember, this was not an innocuous proposition. Before the discovery of penicillin syphilis was treated for prolonged periods (often several years) with drugs such as mercury and arsphenamine which were considerably toxic and which in some cases induced severe secondary effects.

In the 1920s and 30s, the conviction that the Wassermann reaction was highly specific was maintained. A few reports of unusually high percentages of false positive cases were published, but such results were usually attributed to technical errors and inadequate performance of the tests.[36] A better co-ordination among specialists should, it was believed, limit the number of such errors. The Hygiene Committee of the League of Nations organised three international conferences on the serodiagnostics of syphilis (Copenhagen, 1923; Copenhagen, 1928; Montevideo, 1930). There were also two North American conferences organised by the American Society of Clinical Pathologists and the US Public Health Services (1934, 1935–6). In these conferences, samples of both positive and negative sera were distributed to well-known serologists and to serology laboratories in order to estimate the variability between several variants of the Wassermann test, and later to compare data obtained in complement fixation tests to those of flocculation tests (tests based on the principle of directly detecting the presence of 'reagins' in a suspected serum). The comparative tests revealed the existence of differences between individual investigators and between laboratories. These findings reinforced the organisers' conviction that syphilis testing should be performed only in specialised laboratories. They also recommended, whenever possible, checking one kind of test against another (e.g. confirming flocculation results by a complement fixation test). Under optimal conditions, and in the hands of experienced serologists, the tests were, however, found to be trustworthy, and the syphilis testing highly specific.[37]

A similar study, sponsored by the United States Public Health Service in 1935, aimed more specifically at comparing different laboratories. It revealed marked differences between tests performed by expert serologists and those made by standard analysis laboratories. As expected, the state, municipal and private laboratories obtained less trustworthy results, and some of the tests performed in such laboratories showed less than 50% sensitivity, as compared with the 65–88% sensitivity of tests performed by specialists: 'an excellent proof that the methods of these laboratories sadly need correction'. As to the specificity of the tests, the study confirmed the existence of a high (60%) percentage of false positive tests in leprosy, and revealed the – previously unknown – existence of false positive tests (15%) in malaria. The low (and inconsistent) percentage of false positive results found in several other acute diseases (tuberculosis, jaundice, febrile conditions) and in pregnancy was viewed as devoid of practical importance. When sera from patients suffering from acute diseases conducive to false positive results were removed, tests performed in routine laboratories had a low of 91% (and a high of 100%) specificity, while in the hands of specialists

> in general the tests showed a rather high specificity, although four of the participating serologists had a rating of less than 99%, and only five had a rating of 100%. The committee feels very strongly that any test which fails to show a rating of over 99% specificity should be corrected, as it is believed that a false diagnosis of syphilis is, in the words of Moore, 'a major calamity'.[38]

It was felt, however, that at least in expert hands a satisfactory specificity might be achieved.

The faith in the high specificity of the Wassermann reaction was shared by leading microbiologists and immunologists. Jules Bordet affirmed in 1920 that 'the extreme rarity in our countries of leprosy and trypanosomiasis, makes in practice the serodiagnosis of syphilis highly specific'. This affirmation was reiterated by him in the second edition of his book in 1939. And the bacteriologist and historian of medicine William Bulloch explained in 1938 that 'the Wassermann reaction has been practiced to an enormous extent in the diagnosis of syphilis, and is regarded as a test of deadly accuracy'.[39]

While the specificity of the Wassermann reaction and related tests was not questioned before the Second World War, from the mid-1930s on – perhaps as a result of accumulation of clinical experience on this subject – several authors started to question the wisdom of using this reaction as the sole proof of syphilis. In the 1936 edition of *The Principles of Bacteriology and Immunity*, Topley and Wilson discussed the evidence for a low percentage of false positive tests in acute diseases other than syphilis, and affirmed that 'in any case the onus of interpreting the test must rest with the clinician, when he has made due allowance for the stage of the disease, if the case is one of syphilis, and for the possible or probable existence of one of the infections that may sometimes induce similar changes in the serum'. Describing the control of venereal disease in Denmark, the Danish immunologist Thorvald Madson explained in 1937 that 'in no case where the serological result does not agree with clinical symptoms is the doctor to base his diagnosis on serological examination alone'. Finally, a textbook on bacteriology affirmed in 1942 that the Wassermann test 'is a valuable aid in diagnosis, but it must be remembered that it is only an aid and not the diagnosis itself'.[40] A modification attributed to the meaning of a positive Wassermann reaction started thus to be perceptible in the late 1930s and early 1940s. A true revision of the meaning of the positive result of this reaction was made, however, only after the Second World War, as a result of two independent events: the first results of massive routine syphilis testing and the elaboration of specific 'treponemal tests'.

The Wassermann test: the reassessment phase

The belief in the specificity of syphilis testing in all probability played an important role in two decisions: to introduce obligatory pre-marital syphilis tests in several US states, and to start mass syphilis testing of US soldiers during the Second World War. These screening campaigns – the first attempts at large-scale screening for the presence of a given disease – supplied data on Wassermann tests in large sectors of the US population.[41] The results often markedly conflicted with epidemiological observations on the frequency of syphilis in these populations. This finding led some physicians to a strong suspicion that the faith in the high specificity of syphilis tests was mistaken: at least in some sectors of the society the results of these tests might be grossly misleading.

In 1949 a direct test for anti-treponemal antibodies, the 'Nelson test' (later modified and renamed the treponema immobilisation test (TPI)), was developed. In this test living treponemas were immobilised by specific antibodies in the serum.[42] Later another, less expensive 'treponemal test' was developed – the FTA-fluorescein treponemal antibody test. This test revealed the presence of specific anti-treponema antibodies in the serum by the inhibition of the binding of specific, fluorescent anti-treponema antiserum.[43] Unlike the Wassermann test, both 'treponemal tests' detected the presence of specific antibodies in serum of an infected individual; they were therefore based on conventional immunological and bacteriological knowledge. The development of the 'treponemal tests' ended the unique status of syphilis testing and its consequence – the professional isolation of serologists. The switch to treponema-specific tests enabled serologists to replace the esoteric terminology of their speciality[44] by the shared language of biological specificity and facilitated therefore the integration of serology in the mainstream of biological research.

The development of new methods of testing for syphilis made possible the comparison between the 'non-treponemal' (or 'reagin-based') syphilis tests and the 'treponemal tests' based on the presence of specific antibody and viewed as trustworthy indicators of infection with Treponema pallidum. This comparison had confirmed the suspicions of epidemiologists: the specificity of the non-treponemal tests was found to be strongly dependent on the prevalence of infection with Treponema pallidum in the tested population. The 'non-treponemal' tests were found to have a surprisingly low specificity in populations with low incidence of clinical syphilis. In 1952 two American specialists, Drs Moore and Mohr explained that analysis of the results of screenings in large sectors of the US population and verification of the results through the treponema immobilisation test 'has led us to express the epidemiological opinion that in certain population groups in the United States (especially in white persons of relatively high socioeconomic status in the Northeastern, Northern and Northwestern states) at least half of the seropositive reactors discovered in mass blood testing do not have syphilis at all, but do instead have biologically false positive reactions'.[45] Thus the introduction of a new family of syphilis tests had resulted in redefinition of the meaning of a positive result in a 'non-treponemal' test for syphilis and in the creation of a new nosologic entity of 'biological false positives' (BFP), that is individuals who have a high level of 'Wassermann reagins' in their serum and tested negative in 'treponemal tests.'

Moore's and Mohr's findings were confirmed by other studies which demonstrated the inverse relation between the percentage of 'biologically false positive' results and the incidence of syphilis in the tested population.[46] For example, in an analysis of the frequency of false positive results in hospitalised patients in Massachusetts during the years 1954–61 a clear-cut correlation between socio-economic status, race and the frequency of BFP was found. Thus while among the black patients of a public hospital 97% of the sera positive in a 'non-treponemal' flocculation test (Hinton test) were found positive in a specific 'treponemal test' (TPI), among the white patients of private clinics only 59% of the Hinton positive sera were found positive in the TPI test.[47] Tests of populations with no known health problems (in contrast to patients in a hospital) showed even higher rates of 'biological false positives'. For example, among the 3,123 persons tested in California in 1962 and found to have a positive 'non-treponema test', 70% were described as 'BFPs'.[48]

Moore and Mohr divided the 'biologically false positive' reactions into two categories: the 'acute BFPs' and the 'chronic BFPs'.[49] 'Acute BFPs' (that is transitory positive Wassermann reactions that may appear in patients suffering from acute febrile diseases) are viewed today as relatively unimportant laboratory artifacts. This is not the case with 'chronic BFPs' – a persisting positive response in 'non-treponemal' syphilis tests. When 'Wassermann reagins' ceased to be exclusively associated with a treponemal infection, physicians were able to observe that the persistence of these 'reagins' in the serum may be an early indication of a severe chronic disorder such as auto-immune disease, collagen or vascular disease, rheumatoid arthritis, heart or liver disease. In the 1950s and 60s the centre of interest in reagin-based tests shifted from the diagnosis of syphilis to the 'diagnosis of BFP'. The description of the 'chronic BFP' state allowed therefore a redefinition of the failures of specificity of the 'non-treponemal' tests as a 'search for a BFP diagnosis'.

A positive Wassermann test, once viewed as a manifestation of a specific disease, acquired in the 1950s and 60s the status non-specific diagnostic indication, not unlike, e.g., abnormal blood sedimentation rate.[50] Physicians stressed the importance of 'BFP diagnosis' in young women, because in about 20% of such cases 'chronic BFP' was the earliest sign of a severe auto-immune disorder – lupus erythrematosus. Non-treponemal tests were found to be positive in other auto-immune diseases too, and in such cases the diagnosis was further complicated by the fact that in these diseases the specific treponemal tests were also often positive.[51] It was shown that in 20 to 25% of the cases 'chronic BFP' was linked with a vast array of chronic systemic disorders. Other conditions conducive to a chronic BFP state were determined to be heroin addiction, the use of certain anti-hypertension drugs and aging: about 10% of persons aged seventy to eighty were found to be BFP. Finally in numerous cases of 'chronic BFP' the reason for chronic persistence and, in some cases, family occurrence, of high levels of 'Wassermann reagins' in the serum remains unknown. The observation that high levels of 'Wassermann reagins' in the serum may be associated with a vast array of chronic diseases, together with the discovery of a highly efficient syphilis treatment – penicillin – radically modified the meaning of a positive Wassermann reaction for a patient. Before the discovery of antibiotics a physician was in some cases happy to be able to announce to a patient that in all probability he/she did not have syphilis and his/her positive Wassermann reaction was a laboratory mistake. Later the opposite was often true: a physician might be happy to explain to a patient that finally the reason for his/her persisting positive tests was nothing worse than syphilis.[52]

Conclusions

The history of the Wassermann reaction is far from being a story of a failure. In the early twentieth century the Wassermann test contributed to medical knowledge by reinforcing the long-suspected link between the primary syphilitic infection and later complications such as tabes or aortal aneurysm. It had important practical effects too: often this test had allowed the confirmation of a diagnosis of syphilis, and led to a treatment which had a real anti-treponemal efficiency. Moreover, the belief in the efficiency of the test and the treatment of syphilis strengthened the pragmatic view of this disease, and contributed to the development of a network of venereal disease clinics, which, even before the penicillin era, helped to curb the infection rate.

The 'non-treponemal tests' have maintained their usefulness up to the present: although new, more specific tests for syphilis have been developed, reactions based on the presence of 'Wassermann reagin' in the serum (e.g. Venereal Disease Research Laboratory test (VDRL)) are still widely applied today. 'Reagin-based' reactions, which are perceived as tests which possess an adequate sensitivity but very low specificity, have become the first step in a laboratory diagnosis of syphilis. During mass screening campaigns for syphilis, the main goal of these tests has been to eliminate the bulk of non-syphilitic sera, and thus artificially transform a population with a very low incidence of syphilis into one with a high incidence. In such a population, the accuracy of the more specific (but not absolutely specific) treponemal tests is viewed as very high. The 'reagin-based' tests which reveal the presence of active treponemal infection are also very useful in monitoring the treatment of confirmed cases of syphilis.[53] However, before the discovery of antibiotics, the Wassermann reaction was a mixed blessing. A positive test was viewed – in particular in the first period of enthusiasm for the new method – not as a diagnostic aid, but as an infallible proof of treponemal infection. As a consequence, thousands of persons who today would be defined as BFP were diagnosed with syphilis. They suffered not only from the psychological and social consequences of syphilis diagnosis – fear, guilt, shame and social opprobrium – but also from the severe toxic effects of the standard anti-syphilitic treatments.[54]

In the 1910s the Wassermann test represented the peak of contemporary medical science, and was viewed as an exemplary case of successful transfer of knowledge from the laboratory to the clinics. Before the Second World War the specialists believed that the continuation of the previous efforts of better standardisation of the reaction by serologists and a better understanding of the chemical nature of the Wassermann test by the fundamental scientists (or, as the unorthodox immunologist Fleck believed, a better understanding of the nature of serological reactions in general) will unfailingly lead to further improvements in syphilis testing.[55] From a more recent point of view the collective efforts of specialists in the 1920s and 30s may, however, appear singularly ineffective. Studies of the mechanism of the 'reagin' reaction, improvements of the technical aspects of the tests, comparative tests made on samples containing high percentages of positive sera, or the accumulation of thousands of papers dealing with small-scale syphilis testing, could not lead to the identification of an important discrepancy between the results of 'non-treponemal' tests for syphilis and the prevalence of treponemal infection in a given population.[56] Only the ulterior conjunction of two events – the development of specific 'treponemal tests' and the analysis of results of mass screening for syphilis – made possible the observation that (a) as a rule, the percentage of 'false positive' responses in a diagnostic test was dependent on the prevalence of a given pathology in the tested population and (b) regarding syphilis, numerous chronic diseases, the symptoms of which may be confused with those of tertiary syphilis, induce 'modifications of the serum' similar to those induced by a treponemal infection.

With the advent of penicillin syphilis has lost its threatening character, and anti-syphilitic treatment most of its dangers. But new epidemic diseases continue to appear,[57] and the obvious present parallel to syphilis is the AIDS epidemic. The similarity between these two diseases is not limited to the fact that both are sexually transmitted. AIDS, like syphilis, is a chronic, slowly developing illness, in which a long latent stage separates the initial – sometimes asymptomatic – infection from a possible late onset of severe, multiform complications. With syphilis, as with AIDS, 'the long term significance of a person being seropositive is unclear until many years of observation of the disease's natural history have elapsed. The choice of therapy remains controversial, particularly for persons with long-standing, asymptomatic infection. Persistent seropositivity – even after the patient has received an appropriate therapy – frequently results in apprehension and stigmatization.'[58] Finally with AIDS, as with syphilis, the development and the rapid diffusion of tests for the detection of the infection have been fuelled by the powerful prevailing social attitude toward the problems of this disease, and 'the existence of a social tension seeking relief in research'.[59]

It is important to note that the lessons of syphilis testing have not been lost and they were remembered during the development of tests for AIDS. Unlike the Wassermann test and other 'non-treponemal' tests for syphilis, the HIV tests are based on the detection of either specific viral components, or of specific antibodies directed against viral antigens. Moreover, statisticians and epidemiologists have been from the very beginning associated with the development and application of HIV tests. The problem of the high ratio of 'false positives' in low risk populations, and the social cost of such 'false positives' have been important arguments in debates on mandatory or large-scale AIDS testing.[60] But although the scientific basis of HIV tests is in better agreement with the present scientific knowledge than was the case for the Wassermann test, the clinical and epidemiological meaning of the results of these tests is far from being entirely elucidated. Routine AIDS testing, based on tests which detect the presence of anti-HIV antibodies, is still facing two important problems. One is the existence of false-positive results, e.g. in parenteral drug users, or in individuals suffering from a variety of tropical diseases.[61] The other is the existence of the 'silent' phase of the disease during which the level of anti-HIV antibodies in the serum is too low to allow their detection by routine methods.[62] Moreover, the clinical and epidemiological interpretation of tests based on the measurement of anti-HIV antibodies is further complicated by the fact that HIV directly attacks its host's immune system, altering, among other things, his/her capacity to produce antibodies.[63]

The uncertainty about AIDS testing (and about other aspects of HIV-induced pathology as well) is acknowledged by the scientists.[64] It is, however, often viewed merely as a temporary obstacle. There is a widely shared conviction that the important facts about HIV infection are already known and AIDS studies are firmly engaged on the right road. The continuation of the present investigations should therefore lead to a much better understanding of the pathology, epidemiology and the natural history of HIV infection.[65] The history of the Wassermann reaction reminds us, however, of the possible fragility even of seemingly solid and uncontestable 'medical facts'. One cannot avoid the transformation of some of today's 'facts' into tomorrow's 'errors'. What perhaps may be avoided – and probably might have been at least partly avoided in syphilis testing – is an excessive enthusiasm for the latest scientific innovations and an undue haste in their application to the clinics. '*Primum non nocere.*'

Acknowledgements

I am indebted to Virginia Berridge, Gad Freudenthal, Giora Hon, Nancy Rockafellar, Philip Strong and Robert Westman for their comments on an earlier version of this paper.

NOTES

1 Ludwik Fleck, *Genesis and Development of a Scientific Fact*, trans. Fred Bradley and Thaddeus Trenn (Chicago, 1979 (1st edn, 1935)), xxviii.

2 *Ibid.*, 15; Boris Zalc, 'Some comments on Fleck's interpretation of the Bordet–Wassermann reaction in view of present biochemical knowledge', in Robert S. Cohen and Thomas Schnelle (eds.), *Cognition and Fact: Materials on Ludwik Fleck* (Dordrecht, 1986), 399–406.

3 Julius Citron, *The Methods of Immunodiagnostic and Immunotherapy* (Leipzig, 1910), quoted in Fleck, *Genesis and Development*, 58.

4 Ludwik Fleck, 'O swoistych cechach myslenia serologicznego' ('Some specific features of the serological way of thinking') in W. Nowicki and D. Szymkiewicz (eds.), *Papers of the XVth Meeting of Polish Physicians and Biologists, Lwow, July 4–7, 1939* (n.p., n.d.), 287–99; English translation in *Science in Context*, 2 (1988), 343–4.

5 F. R. Schaudinn and E. Hoffmann, 'Vorlaüfiger über das Vorkommen von Spirochaeten in syphilischen Krankheitproducten und bei Papillomen', *Arbeiten aus dem Kaiserlichen Gesundheitsamte*, 22 (1905), 527–34.

6 Jules Bordet and Octave Gengou, 'Sur l'existence des substances sensibilitrices dans la plupart des sérums antimicrobiens', *Annales de L'Institut Pasteur*, 15 (1901), 289–302.

7 August Wassermann, Albert Neisser and Carl Bruck, 'Eine serodiagnostische Reaktion bei Syphilis', *Deutsche medizinische Wochenschrift*, 48 (1906), 745.

8 A. Marie and Constantin Levaditi, 'Les "anticorps syphilitiques" dans le liquide cephalo-rachidien des paralytiques généraux', *Annales de L'Institut Pasteur*, 21 (1907), 138–55; P. Fleishmann and W. J. Butler, 'Serum diagnosis of syphilis', *Journal of the American Medical Association*, 49 (1907), 934–8.

9 Constantin Levaditi and J. Roché, *La Syphilis: expérimentation, microbiologie, diagnostique* (Paris, 1909), 138–40; Fleck, *Genesis and Development*, 70–5. The historical name 'reagin' may be misleading, because later a very different category of antibodies – the IgE antibodies, active in allergic reactions – were also called 'reagins'.

10 Levaditi and Roché, *La Syphilis*, 133–4.

11 William Litterer, 'Serodiagnosis of syphilis', *Journal of the American Medical Association*, 53 (1909), 1537–41; James M'Intosh, 'The sero-diagnosis of syphilis', *The Lancet*, 1 (1909), 1515–21.

12 Stephan Mutermilch, 'Sur la nature des substances qui provoquent la réaction de

Wassermann dans le sérum des syphilitiques et des lapins trypanosomies', *Comptes Rendus de la Société de Biologie* (Paris), 67 (1909), 125–7. This hypothesis was first evoked by Weil. E. Weil, 'Uber den Leusantikörper nach weis im Blute von Luetischen', *Wiener klinische Wochenschrift*, 18 (1907), 527.

13 Jules Bordet, *Traité de l'immunité dans les maladies infectieuses* (Paris, 1920), 433–47; Jules Bordet, *Bacteriologie, parasitologie, infection et immunité* (Brussels, 1927), 162–9.

14 Marc Rubinstein, *Traité pratique de sérologie et de diagnostic* (Paris, 1921), 240; Fleck, *Genesis and Development*, 65; Arthur M. Silverstein, *A History of Immunology* (New York, 1989), 125–9.

15 Ivy McKenzie, 'The serum diagnostic of syphilis', *Journal of Pathology and Bacteriology*, 13 (1909), 311–24; Carl H. Browning, John Cruikshank and Ivy McKenzie, 'Constituent concerned in the Wassermann syphilis reaction, with special reference to leicithin and cholesterin', *Journal of Pathology and Bacteriology*, 14 (1910), 484–502; Paul Gastou and A. Girault, *Guide pratique du diagnostic de la syphilis* (Paris, 1910); Armand Deliele, *Techniques de diagnostic par la methode de deviation de complement* (Paris, 1911).

16 Karl Landsteiner, *The Specificity of Serological Reactions* (Cambridge, Mass., 1947), 102–4.

17 Henry Eagle, *The Laboratory Diagnosis of Syphilis* (London, 1937); Jules Bordet, *Traité de l'immunité* (2nd edn, Paris, 1939), 492–515.

18 Flocculation tests directly reveal the presence of the 'reagin' in the serum. The first flocculation tests were developed in the 1920s. Reuben Kahn, *The Kahn Test: A Practical Guide* (Baltimore, 1928).

19 Fleck, *Genesis and Development*, 78–81, xxviii.

20 Fleishmann and Butler, 'Serum diagnosis of syphilis', 938.

21 Levaditi and Roché, *La Syphilis*, 129; William J. Butler, 'Serum diagnosis of syphilis', *Journal of the American Medical Association*, 51 (1908), 824–30, on 830.

22 Litterer, 'Serodiagnosis of syphilis', 1538.

23 M'Intosh, 'The sero-diagnosis of syphilis', 1515.

24 Hideyo Noguchi, *Serum Diagnosis of Syphilis* (Philadelphia and London, 1910), 109.

25 Hideyo Noguchi, 'A new and simple method for the serum diagnosis of syphilis', *Journal of Experimental Medicine*, 11 (1909), 392–401; Hideyo Noguchi, 'The serodiagnostic of syphilis', *Journal of the American Medical Association*, 53 (1909), 934–6.

26 'Serodiagnosis of syphilis: abstract of discussion', *Journal of the American Medical Association*, 53 (1909), 1540–1.

27 Noguchi, in 'Serodiagnosis of syphilis: abstract of discussion', 1540.

28 E. R. Stitt, *Practical Bacteriology, Blood Work and Animal Parasitology* (Philadelphia, 1914), 154.

29 Carl H. Browning and Ivy McKenzie, 'The biological syphilis reaction: its significance and method of application', *The Lancet*, 1 (1909), 1521–3, on 1523.

30 P. Mauriac, 'Conclusions fournies par trois cent cas de séro-réaction de Wassermann', *Comptes Rendus de Séances de la Société de Biologie*, 66 (1909), 668–70.

31 Litterer, 'Serodiagnosis of syphilis', 1539.

32 Data reproduced by Gastou and Girault, *Guide pratique du diagnostic de la syphilis*, 85–9.

33 D. Leredde, *La Réaction de Wassermann* (Paris, 1912), 28, 29–30.

34 Mauriac, 'Conclusions fournies par trois cent cas', 669; Leredde, *La Réaction de Wassermann*, 30.

35 M'Intosh, 'The sero-diagnosis of syphilis', 1520; Leredde, *La Réaction de Wassermann*, 30, 42.

36 Rubinstein, *Traité pratique de sérologie*, 219–22.

37 Theodor Vogelsang, *Séro-diagnostic de la syphilis* (Bergen, 1940), 24–30.

38 H. H. Hazzen, 'The serodiagnosis of syphilis', *Journal of the American Medical Association*, 108 (1937), 785–8.

39 Bordet, *Traité de l'immunité* (1st edn, 1920), 444; Bordet, *Traité de l'immunité* (2nd edn, 1939), 506; William Bulloch, *The History of Bacteriology* (London and New York, 1938), 283.

40 W. W. C. Topley and G. S. Wilson, *The Principles of Bacteriology and Immunity* (London, 1936), 1441; Thorvald Madsen, *Lectures on Epidemiology and Control of Syphilis, Tuberculosis and Whooping Cough* (Baltimore, 1937), 11; T. B. Rice, *A Textbook of Bacteriology* (Philadelphia and London, 1942), 487.

41 Allan M. Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States since 1880* (2nd edn, New York and Oxford, 1987), 147–52.

42 Robert A. Nelson and Manfred M. Mayer, 'Immobilisation of Treponema pallidum in vitro by antibody produced in syphilitic infection', *Journal of Experimental Medicine*, 89 (1949), 369–93.

43 Wolfgang R. Joklik and David T. Smith, *Zinser's Microbiology* (15th edn, New York, 1972), 644–50.

44 Fleck, 'Some specific features of the serological way of thinking'.

45 J. E. Moore and C. F. Mohr, 'Biologically false positive serological tests for syphilis', *Journal of the American Medical Association*, 150 (1952), 467–73, on 471.

46 Frederick Sparling, 'Diagnosis and treatment of syphilis', *New England Journal of Medicine*, 284 (1971), 642–53. Syphilis testing was the first case of mass screening for the presence of a pathological condition. It allowed therefore the establishment of the epidemiological principle that in such screenings specificity is inversely linked to prevalence.

47 Nicholas J. Fiumara, 'Biologically false positive reactions for syphilis', *New England Journal of Medicine*, 268 (1963), 402–5.

48 C. Carpenter, R. A. Clair and R. A. Broak, 'Tests for syphilis: increasing incidence of false positive reactions as measured by Treponema pallidum immobilization', *California Medical Journal*, 103 (1965), 13–15.

49 Moore and Mohr, 'Biologically false positive serologic tests'.

50 D. L. Tufanelli, K. D. Wuepper, L. L. Bradford and R. M. Wood, 'Fluorescent treponemal antibody absorption tests: studies of false positive reactions to tests for syphilis', *New England Journal of Medicine*, 276 (1967), 258–62; D. L. Tufanelli, 'Aging and false positive reactions for syphilis', *British Journal of Venereal Diseases*, 42 (1966), 40–1; G. S. Wilson and A. Miles, *Topley's and Wilson's Principles of Bacteriology, Virology and Immunity* (6th edn, London, 1975), 2315–19; P. Balows and W. J. Hausler, *Diagnostic Procedures for Bacterial,*

Mycotic and Parasitic Infections (Washington, DC, 1981), 631–74; E. H. Lenuette, A. Ballows, W. J. Hauser and H. J. Shadomy, *Manual of Clinical Microbiology* (Washington, DC, 1985), 910–21.

51 J. L. Miller, M. Brodey and J. H. Hill, 'Studies on the significance of biologically false positive reactions', *Journal of the American Medical Association*, 164 (1957), 1461–6; M. A. Harvey, 'Auto-immune disease and the chronic biologic false positive tests for syphilis', *Journal of the American Medical Association*, 182 (1962), 513–18; Sidney Olansky, 'Current serodiagnostic and treatment of syphilis', *Journal of the American Medical Association*, 198 (1966), 165–8; S. J. Kraus, J. R. Haserick and N. A. Lonz, 'Atypical FIA-ADS fluorescent tests in lupus erythrematosus patients', *Journal of the American Medical Association*, 211 (1970), 2140–4; F. S. Aschar and R. Miller, 'Serological test for syphilis in diseases of the thyroid', *Journal of the American Medical Association*, 213 (1970), 872.

52 Fiumara, 'Biologically false positive reactions for syphilis'.

53 L. L. Bradford, *et al.*, 'FTA-200, FTA-ABS and TPI tests in serodiagnosis of syphilis', *Public Health Reports*, 80 (1965), 797–804; US Department of Health, Education and Welfare, *Manual of Test for Syphilis* (Atlanta, 1969); Russel C. Johnson (ed.), *The Biology of Parasitic Spirochetes* (New York, 1976); US Department of Health, *Manual of Tests for Syphilis*; L. L. Bradford and S. A. Larsen, 'Serological tests for syphilis', in Lenuette *et al.* (eds.), *Manual of Clinical Microbiology*, 910–21.

54 Walsh McDermott, 'Evaluating the physician and his technology', *Dedalus*, 106 (Winter 1977), 135–57, on 144.

55 The origins and physiological role of the 'Wassermann reagin' are not much better understood today than they were eighty years ago. Wilson and Miles, *Topley's and Wilson's Principles of Bacteriology*, 2318–19; Silverstein, *A History of Immunology*, 169. Recently, cases of syphilis in AIDS patients have pointed to a greater than suspected role of the patient's immune response in the prevention of neurosyphilis and called the attention of physicians to the insufficiency of the understanding of immune mechanism in syphilis. Edmund C. Tramont, 'Syphilis in the AIDS era', *The New England Journal of Medicine*, 316 (1987), 1600–1; Donald R. Johns, Maureen Tierney, and Donna Felenstein, 'Alternation in the natural history of neurosyphilis by concurrent infection with the human immunodeficiency virus', *Journal of the American Medical Association*, 316 (1987), 1569–72.

56 For discussion on'unexpected errors', see Giora Hon, 'Experimental errors: an epistemological view', in Paul Weingartner and Gerhard Schurtz (eds.), *Philosophy of the Natural Sciences: Borderline Questions* (Vienna, 1989), 368–76; Giora Hon, 'Franck and Hertz versus Townsend: a study of two types of experimental error', *Historical Studies in the Physical and Biological Sciences*, 20 (1989), 79–106.

57 Charles Nicolle, *Destin des maladies infectieuses* (Paris, 1933).

58 Dale N. Lawrence, 'The acquired immunodeficiency syndrome: what it can teach us', Banquet address delivered by the author on 24 April 1984, at the Bay Harbor Inn, Tampa, Florida. Reproduced in A. Szentiavang and H. Friedman, *Viruses, Immunity and Immunodeficiency* (New York and London, 1986), 189–94, on 189–90.

59 Fleck, *Genesis and Development*, 77.

60 Klemens B. Meyer and Stephen G. Pauker, 'Screening for HIV: can we afford the false-positive rate?', *The New England Journal of Medicine*, 317 (1987), 238–41; Robin Weiss and Samuel O. Thier, 'HIV testing is the answer – what is the question?', *The New England Journal of Medicine*, 319 (1988), 1010–12.

61 James D. Moore, Edward J. Cone and Steve S. Alexander, 'HTLV-III seropositivity in 1971–1972 parenteral drug abusers – a case of false positives or evidence of viral exposure', *The New England Journal of Medicine*, 314 (1986), 1387–8; Robert J. Biggar, Paul L. Gigase, Mads Melbye *et al.*, 'Elisa HTLV retrovirus antibody reactivity associated with malaria and immune complexes in healthy Africans', *The Lancet*, 2 (1985), 520–3; Ulla Bredberg Raden, John Kiango, Fred Mhalu and Gunnel Biberfield, 'Evaluation of commercial enzyme immunoassays for anti-HIV-1 using East African sera', *AIDS*, 2 (1988), 281–5; Neil T. Constantine, Emile Fox, E. A. Abbate and James N. Woody, 'Diagnostic usefulness of five screening assays for HIV in an east African city where prevalence of infection is low', *AIDS*, 3 (1989), 313–17.

62 Richard G. Marlink, Jonathan S. Alan, Mary McLane *et al.*, 'Low sensitivity of Elisa testing in early HIV infection', *The New England Journal of Medicine*, 315 (1986), 1549; Sheldon H. Landesman, Harold M. Ginzburg and Stanley H. Weiss, 'Special report: the AIDS epidemic', *The New England Journal of Medicine*, 312 (1985), 521–5; Annamari Ranki, Sirkka-Lisa Valle, Minerva Krohn *et al.*, 'Long latency preceded overt seroconversion in sexually-transmitted immunodeficiency virus infection', *The Lancet*, 2 (1987), 589–93; Michael Loche and Bernard Machi, 'Identification of HIV infected seronegative individuals by a direct diagnostic test based on hybridization to amplified viral DNA', *The Lancet*, 2 (1988), 418–21; John W. Ward, Scott D. Holmberg, James R. Allen *et al.*, 'Transmission of human immunodeficiency virus (HIV) by blood transfusions screened negative for HIV antibody', *The New England Journal of Medicine*, 318 (1988), 473–8; David T. Imagawa, Moon H. Lee, Steven M. Wolinsky *et al.*, 'Human deficiency virus type I in homosexual men who remain seronegative for prolonged periods', *The New England Journal of Medicine*, 320 (1989), 1458–62; William A. Haseltine, 'Silent HIV infections', *The New England Journal of Medicine*, 320 (1989), 1487–9.

63 Maxime Seligmann, Leonard Chess, John L. Fahey *et al.*, 'AIDS – an immunological evaluation', *The New England Journal of Medicine*, 311 (1984), 1286–92; P. Volberding, 'AIDS – variations on a theme of cellular immune deficiency', *Bulletin de l'Institut Pasteur*, 85 (1987), 87–94; Anthony Fauci, 'The human immunodeficiency virus: infectivity and mechanisms of pathogenesis', *Science*, 239 (1988), 617–22.

64 Jay A. Levy, 'Mysteries of HIV: challenges for therapy and prevention', *Nature*, 333 (1988), 519–22; Robert S. Root-Bernstein, 'Do we know the cause(s) of AIDS?', *Perspectives in Biology and Medicine*, 33 (1990), 480–500.

65 Margaret A. Hamburg and Anthony Fauci, 'AIDS the challenge to biomedical research', *Dedalus*, 118, 2 (Spring 1989), 19–40; David Baltimore and Mark B. Feinberg, 'HIV revealed: towards a natural history of the infection', *The New England Journal of Medicine*, 321 (1989), 1673–5.

5

The politics of international co-ordination to combat sexually transmitted diseases, 1900–1980s

PAUL WEINDLING

Organisations for the prevention and cure of sexually transmitted diseases (STDs) have been battlegrounds for social conflicts and international tensions. Debates on control of STDs expose tensions between officially condoned pro-natalism and social purity movements, and dissident internationally minded feminists, socialist sympathisers and pacifists, demanding removal of police controls on public morality, sex education, freely available contraceptives and the socialisation of health services. Medical scientists were themselves divided between these contrasting viewpoints. The emergence of any unitary international consensus on STDs let alone any single authority has been undermined by governmental hostility to a supranational agency, controversies over medical power and the efficacy and distribution of new drugs like salvarsan and penicillin, and by birth control propagandists challenging traditional notions of the family.

Imperialist conferences and conflicts

Imperialist concerns with promoting national efficiency by combating physical degeneration and declining birth rates arose at the same time that campaigners for the abolition of police controls on prostitution were seeking comprehensive strategies to prevent and treat STDs throughout the totality of populations. Voluntaristic models of self-help clashed with state and policing regulatory measures. Whether there should be targeting of specific groups like prostitutes or education of total populations (recognising that STDs were not a monopoly of prostitutes) were issues. The extent that STDs were precipitated by poverty, the lack of basic sex education or immorality was keenly debated. Imperial powers regarded STDs as a threat to the family, to military and economic power and to the nation's future generations; syphilis was a major cause of blindness and other disabilities, and concern increased over gonorrhea as a cause of sterility and miscarriage.

The first initiatives in international co-ordination of efforts to control STDs were the *Conférence internationale pour la prophylaxie de la syphilis et des maladies vénériennes* held in Brussels during 1899 and a second conference in 1902.[1] Here the powers of police and medical authorities were criticised by feminists and socialists. A more moralistic tone was struck at the International Congress for Combating the Traffic in Women held by voluntary organisations in 1899. The foundation of the International Bureau for the Suppression of the Trade in Women and Children in 1904 led to a French government-sponsored conference. There resulted distinct strategies with different historical lines of development: medical controls on sexually transmitted diseases, and moral and policing efforts to control prostitution as an international vice.

These differences remained unresolved when societies to combat 'venereal diseases' were established first in France in 1901, in Germany in 1902, in the United States in 1905 and (significantly later) in Great Britain in 1914.[2] These societies had both lay and medical membership with greater lay involvement in the United States and Britain, and domination by the medical profession in continental Europe, where dermatology and venereology were more highly developed as medical specialisms. The pace-setting French and German societies placed greater stress on public understanding of medical means of prevention and treatment than the Americans emphasising moral education.[3] The Germans took an interest in prevention by recommending Alexander Metchnikov's antiseptic ointment for self-disinfection, condoms and highly controversial preventive health checks on prostitutes.[4] The Prussian state supported diagnosis with Wassermann testing, as well as developing curative chemotherapy with salvarsan.[5] The German sickness insurances and state authorities were also interested in compiling statistics on the incidence of STDs.

During the First World War there was a fiercely debated shift of priorities from moralistic notions of self-control to improving medical facilities. Military and civilian authorities established networks of primary health care for STDs. Improved facilities for diagnosis and treatment for soldiers and civilians became available in new outpatient clinics and dispensaries. To the indignation of campaigners for moral purity there was a greater readiness on the part of the authorities to accept condoms as a barrier to infection.[6] This coincided with the extension of welfare facilities to cater for the needs of single mothers and working women. Whereas imperialist ideologies prior to war had initially reinforced pro-natalism, during the war there was a new acceptance that improved medical and welfare provision as well as greater availability of condoms would help to diminish STDs.

Inter-war health and welfare bodies

Control of STDs was crucial in the transition from war to peace with the fear that infected soldiers might spread STDs among the civilian population. Groups targeted as reservoirs of STDs were – besides prostitutes – the armed services, demobilised soldiers and sailors, and merchant navies. The risks from STDs to seamen and to other migrant workers was a stimulus for free and universal provision of treatment and diagnosis irrespective of nationality. Radicals, critical of targeting specially infective groups, pointed out that socialisation of medicine with free and universal medical treatment for all health problems could cover STDs so rendering redundant various forms of special care.

The problems of establishing an international health organisation were compounded by disagreements between the allies, which resulted in competing international agencies. These included: the Health Organisation of the League of Nations (LNHO), the International Labour Office (ILO) which had a small medical division, the International Office of Public Health/Organisation internationale d'hygiène publique (OIHP) and the League of Red Cross Societies (LRCS). These bodies had very different constitutions which influenced their policies: the LHNO and OIHP were controlled by constituent states with Britain and France having dominant (but rival) roles. The ILO was a tripartite organisation of states, employers and trade unions, and was much influenced by its first Secretary-General, the French socialist Albert Thomas who challenged the hegemony of national ruling elites on the basis of universalist ideals and conventions. The LRCS had a philanthropic ethos derived from voluntary war work. The problem arose whether these organisations were to be staffed only by a small number of professional experts whose activities were restricted to comparisons of legislation, statistical and technical problems, or whether these international organisations should be able to take autonomous initiatives, and involve a broad range of lay and professional advisers. The LRCS promoted a framework based on US developments in 'social hygiene', which emphasised the need for constituent national societies to undertake preventive educative programmes on a voluntary basis, encouraging personal hygiene, and a sense of individual responsibility for future generations.[7] Certain national Red Cross societies – notably the Norwegian Red Cross – wished to take over the running of seamen's clinics, prompting debates on voluntaryism or state responsibility for STDs.[8]

First World War and post-war fears that soldiers might spread venereal infections to civilian populations enhanced the importance of the LRCS. In April 1919 the Committee (subsequently the League) of Red Cross Societies favoured an international council and central bureau of health with a section for venereal diseases.[9] The LRCS was in an expansionist phase of post-war optimism, which was boosted by the substantial funds from the American Red Cross, when it organised a series of conferences: a Pan-American Conference on Venereal Diseases in December 1920, a Burmese conference, and three regional conferences in western Europe (in Paris under the patronage of the French Ministry of Hygiene in December 1921), in northern Europe (in Copenhagen in

May 1921) and eastern Europe (in Prague in December 1921).[10] Yet the LRCS was at loggerheads with the International Committee of the Red Cross, and misgivings arose at the League of Nations' recognition of the LRCS as a voluntary body, particularly once the LN's own health organisation was formed. When the LRCS moved its headquarters to Paris in 1922, its expansionism was on the wane.

From the time of the Genoa maritime conference of 1920 the issue of venereal diseases among seamen was used by the ILO to assert its right to take initiatives in health matters against the LRCS, the emergent LNHO, OIHP and the National Council for Combating Venereal Disease (NCCVD).[11] In 1924 the ILO conducted a survey of treatment facilities in ports and harbours.[12] Thereafter the ILO gave occasional advice but maintained a 'politique d'abstention' on issues associated with STDs except for the issue of port welfare on which employers' organisations also held strong opinions.[13] The provision of treatment for seamen was taken up by the governmentally oriented OIHP. It secured the Brussels agreement of 1924 that governments should establish services for the treatment of STDs for seamen of all nationalities with medical facilities and drugs available free of charge.[14] The League of Nations felt compelled 'to nominate one or more public health men' to act as technical experts.[15] The initiative passed to governments, and the Belgian government negotiated an agreement of December 1924 for treatment facilities for merchant seamen (using a British-style *carnet* for treatment records). The agreement was endorsed by France and Great Britain but not the USA or USSR.[16] The monitoring of port facilities under the Brussels Agreement was a responsibility of the OIHP.[17] The issue of merchant seamen's welfare continued to preoccupy single-country organisations like the British Red Cross and NCCVD, and prompted efforts to maintain the separation of sailors from indigenous populations by enforcing systems of passes, the fencing in of dock areas and the exclusion of visitors to ships.[18]

The NCCVD was given official blessing by the British government keen to devolve a controversial area of policy to private initiatives.[19] The NCCVD undertook a global role with commissions to the Far East, Mediterranean and West Indies during 1920, and to Constantinople in 1921. In response to the Genoa conference of 1920 and the activities of the LN and ILO, the NCCVD set about improving facilities in ports in Britain and the Empire. In 1921 it distributed leaflets in French, Dutch and Danish on treatment facilities in North Sea ports.[20] Although by January 1922 the LRCS had decided to discontinue its division for combating venereal diseases, Sybil Neville-Rolfe (the formidable Secretary-General of the NCCVD and eugenicist) spurred it into taking further international initiatives, and liaised with Sir George Buchanan, the British representative of the LNHO.[21] Relations with the ILO revolved around the provision of medical and social facilities for sailors.[22]

The ILO and LNHO were suspicious when the Union Internationale contre le

Péril Vénérien (UIPV) was established in Paris in January 1923. But they were forced to support the UIPV by British Ministry of Health Officials arguing in favour of 'voluntary effort' at a national and international level.[23] The recognition of the UIPV meant that the moralistic NCCVD and LRCS (under Sir Claude Hill) could have a major say at an international level. The Director of the Venereal Diseases Section of the LRCS, Emile Weisweiller, became Secretary-General of the UIPV. The UIPV was composed of specialist societies, national Red Cross Societies, state representatives, and technical representatives from the ILO, the LNHO and the International Council of Women.[24] The UIPV was subject to conflicts between member organisations, as it moved from a moralistic Anglo-American position to a stance based on social medicine. British delegates were disappointed at the French dominance over the first congress in May 1923, and overcame French hostility to German participation.[25] Initially the organisation had a Secretariat financed by the LRCS, but by 1925 the UIPV had broken away from the dominance of the LRCS.[26] This can be seen as a reaction to the American-sponsored International Social Hygiene Congress of 1925. While freeing itself from the Anglo-American-dominated LRCS, it remained much influenced by its French location. In 1927 there was a change of Secretary-General from Weisweiller to J.-A. Cavaillon, a French ministerial public health official.[27] Cavaillon's appointment as technical adviser to the LRCS on 'all matters relating to VD' signalled a defeat of the LRCS's moralistic voluntaryism.[28] The UIPV was doggedly Euro-centric, encouraging European states like Sweden (where the state assumed a central role in comprehensive legislation for diagnosis and treatment of STDs since 1918) and Finland to form constituent organisations. Although having members from North and South America, with the exception of a single congress in Tunis, UIPV meetings were in Europe. Colonies and mandated territories were deemed to be represented by the colonial powers.[29] The Germans continued to be members after the Nazi takeover in 1933 – and consequent withdrawal from the LNHO and ILO – and a UIPV conference was held in Cologne in 1937, but the USSR was a conspicuous absentee despite negotiations in 1928.

The British NCCVD attempted to give the UIPV a moralistic tenor. In 1925 the NCCVD became the British Social Hygiene Council (BSHC), responding to the American point of view that attention should be shifted from the infected to the preventive education of the uninfected. It represented a move from the pre-war Franco-German medical models of improved access to treatment and preventive health education to the American stress on morals and personal hygiene with mass propaganda, deploying new media like the radio and cinema and advertising techniques in Health Weeks.[30] The BSHC jealously defended its colonial realm as its legitimate sphere of activity: colonies were discouraged from joining the UIPV in their own right. Given that the UIPV broke away from the American-influenced LRCS, a profound rift between Anglo-American and

European viewpoints can be discerned in 1925. Cavaillon later managed to heal the wounds through co-operation with Mrs Neville-Rolfe (an admiral's daughter and widow of a naval commander) who for her part came out in favour of abolitionism. In 1927 the LRCS resurrected its committee on venereal diseases, but ceded control to the UIPV.[31] The Ports Commission of the UIPV was funded by £1,000 respectively from the British Shipping Federation and the American Social Hygiene Association.[32] Mrs Neville-Rolfe continued to act as a global inspector of treatment facilities. Her vigilance exposed how countries tried to evade their obligations under the Brussels agreement, and she persuaded many port authorities, for example in Hamburg, to provide free diagnosis and treatment for seamen of all nations.[33] In 1928 she was invited to chair and direct the UIPV's Ports Committee, and thereafter took a prominent international role on behalf of the UIPV.[34]

The UIPV's moderately progressive stance meant that despite limited resources, it could claim constructive achievements in facilitating international comparisons and checking excessive policing or under-provision of state resources for diagnosis and therapy. The UIPV did not establish a major journal or other organ of publicity, leaving activities to constituent organisations; but Cavaillon published under UIPV aegis an important study of legislation throughout the world.[35] The UIPV served as a forum for the representatives of various organisations to meet and inspect each other's work in the course of conferences and study tours. Such visits facilitated comparison of different systems of regulation of prostitution and notification of STDs, for example Mrs Neville-Rolfe and the NCCVD studied Scandinavian procedures comparing statistics of the incidence and treatment of STDs with those in Britain.[36] The UIPV encouraged the foundation of national organisations where none existed, co-ordinated propaganda on the risks of infection, sought to remove social and moral stigma as well as any discriminatory measures in medical insurance and social security legislation and insisted on equal moral codes for both sexes.

The UIPV endorsed abolitionist demands for an end to the regimentation of prostitutes, and proposed measures embracing the totality of the population while respecting 'the principle of individual liberty'.[37] Its moralism was reflected in support for the censorship of books and films, and concern over the corruption of youth. It demanded disinfection facilities for merchant seamen and colonial troops, and screening of emigrants and frontier controls for carriers of STDs.[38] It was initially cautious as regards publicity for condoms as a barrier to infection, and – to the chagrin of the Pasteur Institute – condemned Metchnikov's self-disinfection ointment.[39] But by 1930 it was advocating a fully medical programme with self-disinfection as the starting point.[40] Symptomatic of the dominance of a professional lobby was opposition to native practitioners as 'quacks' and it did not seek to establish patients' rights in legislative schemes for compulsory detention and treatment, or in criminal sentences for infecting another with syphilis. The UIPV can be seen as moving away from moralistic concerns or US-dominated social hygiene of the early 1920s to medical and secular viewpoints by the 1930s.

Avoiding birth control

The UIPV like most other international medical organisations had male doctors in leading positions. Sybil Neville-Rolfe of the NCCVD/British Social Hygiene Council (BSHC) was the only woman representative and the only person without medical qualifications. The ILO, LRCS and LNHO also employed very few women, except in spheres concerned with the family and women's welfare. International efforts to protect women and children involved greater numbers of women welfare workers. The League of Nations took up the pre-war standards concerning the minimum age of prostitutes and penalties for procuration in a Convention of 1921. The issue of prostitution was dealt with by a separate social committee which tackled the question of 'white slavery' and 'the suppression of traffic in women and children'.[41] Although the USA was not a member of the League, it was represented on the Committees for Traffic in Women and Children, and on the Child Welfare Committee. The Rockefeller's Bureau of Social Hygiene provided $75,000 funding for an enquiry on the extent of the traffic in Europe, the Mediterranean region and the USA, and in 1930 contributed $125,000 for a Far Eastern survey. The committee supported the development of women police, and co-operation between the International Criminal Police Commission and the Traffic in Women and Children Committee.[42] In 1923 an international convention for the suppression of obscene publications was drawn up, and this was ratified by thirty-five member states by 1929. Some delegates wished to include 'birth control propaganda', although opinions differed over whether this was a special class of obscene literature.[43] The debate revealed the highly moralistic and pro-natalist tenor of the 'social and humanitarian activities' of the LN. The situation exposed the rift between moral and policing solutions to the problem of prostitution, and more strictly medical approaches.

The LNHO concentrated on a restricted range of scientific issues such as the standardisation of the Wassermann and flocculation tests, and of salvarsan therapy. Issues associated with the diagnosis of gonorrhea, soft chancre and other sexually transmitted infections were not tackled. Expert conferences on serodiagnosis were held in London in 1921 and in Paris in 1922. In 1923 a working laboratory conference was held in Copenhagen when 500 specimens from eight countries were tested using different techniques. Further working laboratory conferences were held in Frankfurt am Main, in Geneva in 1928 and in Montevideo in 1930.[44] Laboratories at Copenhagen and London were designated for establishing international standards for pharmaceutical products and vaccines, and the Copenhagen laboratory acted as a centre for studies of salvarsan. The LNHO paid scant regard to the practicalities of financing and gaining public acceptance for serodiagnosis and salvarsan therapies. In 1935 it proposed a protracted forty to sixty week standard treatment for syphilis, which required extensive systems of scientific medicine. Governments' suspicion of international agencies developing autonomously optimum but costly policies encouraged a minimalist reaction; this meant that contraception and the circumstances of non-European populations – particularly regarding non-venereal trypanosomes associated with poor hygiene and poverty – were virtually ignored. The colonial powers became obstructive: thus in 1930 the Secretary of the LNHO argued for its responsibility for the health of 'native populations', but this was strongly objected to by the British representative.[45] International health organisations could not operate on a global scale, and the LNHO was limited to the technical areas. Thus 'education' for the LNHO was not public education or health education in schools but professional postgraduate education, seen as part of the building up of viable professional specialisms of venereology as related to urology or dermatology.

There was broad international consensus over family allowances and over the need to have a system of medical insurance which supported treatment for STDs as for any other disease.[46] Within each member country there were tensions between more moralistic and more secular approaches, which condoned contraception. The League of Nations found itself unable to give frank consideration to – let alone endorse – birth control. Eric Drummond, Secretary-General of the LN was a convert to Catholicism; he opposed discussion of birth control. Dame Rachel Crowdy of the Social Questions Section and members of the Health Secretariat were more sympathetic when invited to attend the World Population Conference, but recognised that they could not act as official representatives of the LN as long as member states had not endorsed birth control. The ILO's constitutional basis provided for greater autonomy. The Director of the ILO, Albert Thomas took a prominent role at the World Population Congress encouraging the American birth control campaigner, Margaret Sanger, and suggesting the need for international research on the solution to population problems.[47] The congress was held in Geneva in 1927, and it inaugurated the International Union on Population. The conference tackled the population expansion as economically and medically damaging from a eugenic point of view, arguing the need for selective welfare benefits and immigration policies.[48] The conference could not advocate birth control as this was too controversial. The medical implications of degenerationism and abortion were discussed, but not the question of STDs. In 1932 the LNHO's committee on maternal and child welfare (chaired by Janet Campbell of the British Ministry of Health) cautiously raised the issues of medical indications for birth control and abortion. There were strong attacks from Catholic medical organisations, and from representatives from Catholic countries during 1932-3.[49] This situation meant that there was reluctance to tackle the complex moral and social issues concerning sex education, contraception and sexually transmitted diseases.

The birth control question was marginalised and consigned to various eugenics organisations and the left-liberal and socialist-inclined Malthusian leagues. Disagreements in Britain between the NCCVD's moralistic stance and the secularists who had in 1919 broken away to establish the Society for the Prevention of Venereal Diseases (SPVD) were projected onto the world stage of the neo-Malthusian and sexual reform movement.[50] Self-disinfection became part of a progressive package which included birth control, abortion, voluntary sterilisation, psycho-analysis, and campaigns for the removal of legal penalties against homosexuality, as well as broader links with feminism, socialism and secularism.[51] The Secretary of the SPVD, Hugh Wansy Bayly, addressed the World League for Sexual Reform Congress, held in London in 1929, arguing that preventive campaigns had been excessively moralistic resulting in 'the suppression of the sexual instinct outside marriage'. The SPVD stressed immediate self-disinfection after risk.[52] Although certain speakers supported the criminalisation of infecting another person with an STD, this was very much a minority attitude for the thrust of the sex reform movement since the abolitionist era was to replace the authority of the police by medical science. It was above all the Soviet Union which was hailed as an international model for radical approaches to STDs. In contrast to moralistic American views, Soviet social hygiene diagnosed prostitution as a result of poverty.[53] The raising of overall standards of prosperity and abolishing unemployment and class inequalities would – it was hoped – result in the disappearance of prostitution. Radical sex reformers like the German physician, Max Hodann, argued that the socialisation of medicine was the best way to tackle STDs. In this way every citizen would have free and equal access to all medical services, and so special measures for control of STDs would be rendered unnecessary. Hodann argued that 'sexphobia' – hostility to all extra-marital sexual relationships – underlay most health education literature on STDs. Thus treating STDs as any other disease and removing all social and moral stigmas was in the view of radical sex reformers a solution to wider problems of poverty and disease.[54]

The post-Second World War era: old conflicts among new bodies

The inter-war coyness over contraception was in marked contrast to the post-1945 attack on the 'population explosion' as a global issue. Whereas the inter-war period was characterised by a plurality of international agencies, the founding of the World Health Organisation (WHO) in September 1948 brought about new possibilities for global strategies. The prior Interim Commission and the WHO continued inter-war trends in social medicine but unified the disparate organisations. It sought support for a revised version of the 1924 Brussels agreement; among echoes of the past was Cavaillon of the UIPV attending as an observer.[55] The technical emphasis on standards was readily adapted to the new potential of penicillin. The WHO took initiatives concerning standardisation of serological tests and in drawing up treatment schedules for penicillin, and called on the facilities of United Nations Relief and Rehabilitation Administration (UNRRA) regarding penicillin manufacture and United Nations International Children's Emergency Fund (UNICEF) for financing penicillin programmes to combat syphilis in pregnant women.[56]

Lay and political pressures meant that inter-war health organisations were fragmented and enfeebled; by way of contrast, the WHO operated on more purely medical foundations. The resulting narrowness was restrictive. Although certain WHO officials and delegates were convinced from the start that birth control was a medical problem, pressure from member governments kept the WHO as a purely 'technical organisation' thereby excluding family planning from its responsibilities.[57] That the Second World War saw the introduction of antibiotics for military and then civilian populations also strengthened the view that sexually transmitted diseases were primarily a medical problem. Lay participation diminished, as the previously active anti-STD public associations became either defunct (as in Germany) or changed their focus (as in Britain where attention shifted to school biology and sex education). This can be seen in WHO's expert Committee on Venereal Infections. Initially the problem of STDs in post-war Europe was a major preoccupation, and can be seen with special concern for Rhine River Boatmen and conditions in Poland. Horizons broadened to endemic trepanosomes in poor countries, and mass penicillin campaigns were launched. Yet WHO initiatives for the eradication of syphilis were unsuccessful. Antibiotics made only a limited impact on gonorrheal infections, and other infections like chancroid were ignored.[58]

A dichotomy continued between population and health problems. Anglo-American influence secured a UN Population Commission in 1946 but its status was downgraded in 1955. In 1969 a UN population programme was initiated with a UN Fund for Population Activities. Although improvements in maternal and child health were recognised as incentives for family limitation, health matters were less of a priority than environmental and economic considerations, and the fundamental concern that world peace could be threatened by imbalance in birth rates.[59] The favouring of the birth control pill and sterilisation in the arising policies has restricted the availability of condoms in developing countries, as their importance in preventing infections was insufficiently appreciated.

The WHO's ideology of public health campaigns remained militaristic resonating with ideological echoes of *fin de siècle* imperialism. The transition from an 'attack phase' (with mass penicillin campaigns) to 'consolidation' (with the establishment of integrated systems of clinics) proved difficult. The hoped for eradication of endemic syphilis and yaws, using an ideal drug or 'magic bullet', was over-optimistic.[60] The WHO found that antibiotics had made little impact on gonorrheal infections, and underlying social problems were not being tackled. It is only recently that the emphasis has changed to primary health care, taking account of local variations in lifestyle, socio-economic structures and cultural values. The WHO recognised the need to deploy only 'socially acceptable technologies' and to encourage lay participation.[61]

Scientism, militarism and state controls have dominated international initiatives.[62] The powers and responsibilities of international organisations remain unresolved. The LNHO was subject to the conflicts between the minimalist tendency for international organisations to act as agencies of epidemiological intelligence for member governments, and the universalist drive to formulate optimum standards so transcending the interests of ruling elites in member states. Action remains a discretionary matter for national health authorities. All too often ruling national elites pose obstacles to humane measures, and there is an inherent narrowness to policies directed by medical elites. The military model of public health campaigns created an authoritarian and coercive ethos. This authoritarian model can be contrasted to alternatives already present in the liberalising movement to abolish state controls on prostitution in the late nineteenth century, and continued by feminists, sex educators and birth control campaigners in the inter-war period.

The primary focus of this account has been the politics of the plurality of inter-war health organisations. Ironically consensus over the UIPV's abolitionist and egalitarian programme over medical and social strategies was only emerging by the early 1930s when the international diplomatic situation was deteriorating. Today's discussions over AIDS resonate with the echoes of early lay criticisms of over-elaborate schemes for medical controls, and suggest the need for respect of cultural diversity and individual needs and feelings, the blending of medical priorities with humanitarian values, democratic accountability and popular participation.

NOTES

1 *Conférence internationale pour la prophylaxie de la syphilis et des maladies vénériennes* (Brussels, 1899). *IIe conférence internationale pour la prophylaxie de la syphilis et des maladies vénériennes* (Brussels, 1902).

2 C. Quétel, *History of Syphilis* (Oxford, 1990), 135. A. M. Brandt, *No Magic Bullet. A Social History of Venereal Disease in the United States since 1880* (expanded edn, New York and Oxford, 1987), 24–6. F. Tennstedt, 'Alfred Blaschko – das wissenschaftliche und sozialpolitische Wirken eines menschenfreundlichen Sozialhygienikers im Deutschen Reich', *Zeitschrift für Sozialreform*, 25 (1979), 513–23, 600–14, 646–67. P. J. Weindling with U. B. S. L. Slevogt, *Alfred Blaschko*

(1858–1922) and the Problem of Sexually Transmitted Diseases in Imperial and Weimar Germany (Oxford, in press).

3 *Royal Commission on Venereal Diseases in the United Kingdom. Minutes of Evidence* (London, 1916), 104–7, evidence of A. Blaschko concerning the German Society, 5 June 1914.

4 S. Leibfried and F. Tennstedt (eds.), *Kommunale Gesundheitsfürsorge zwischen Kaiserreich und Nationalsozialismus – autobiographische, biographische und gesundheitspolitische Anmerkungen von Dr Georg Loewenstein* (Bremen, 1980). U. Linse, 'Alfred Blaschko: Der Menschenfreund als Überwacher. Von der Rationalisierung der Syphilis-Prophylaxe zur sozialen Kontrolle', *Zeitschrift für Sexualforschung* (1989), 301–16.

5 L. Fleck, *Genesis and Development of a Scientific Fact* (Chicago and London, 1979), 68–70.

6 E. H. Beardsley, 'Allied against sin: American and British responses to venereal disease in World War I', *Medical History*, 20 (1976), 189–202. B. A. Towers, 'Health education policy 1916–1926: venereal disease and the prophylaxis dilemma', *Medical History*, 24 (1980), 70–87.

7 League of Nations archives, Geneva (hereafter LN), 12B/27351/5923, 'Memorandum. Co-operation between the League of Red Cross Societies and other International Health Organisations' (*c.* August 1925).

8 National Council for Combating Venereal Diseases/British Social Hygiene Council papers, Wellcome Unit for the History of Medicine Oxford (hereafter NCCVD/BSHC papers), Imperial and International Committee, 1 Oct. 1926, 31 May 1933.

9 *Proceedings of the Medical Conference Held at the Invitation of the Committee of Red Cross Societies, Cannes, France April 1 to 11, 1919* (Geneva, 1919), 82–96.

10 S. Neville-Rolfe, 'North European opinion on the venereal disease problem', *Health and Empire*, 1 (1921–2), 7. I. F. Ritchie, 'Western European conference on venereal diseases', *Health and Empire*, 1 (1921–2), 38–9.

11 International Labour Office archives, Geneva (hereafter ILO), HY 1100/1/0, L 6/1, concerning the opposition of Crowdy.

12 ILO HY 1000/4/3, 7 March 1924, Weisweiller to Thomas. ILO to Union Internationale, 2 April 1924.

13 ILO HY 1000/4/5, Memorandum by A. Thomas that the ILO should liaise with the UIPV, without Carozzi attending its meetings; HY 1000/4/6, Memorandum by Carozzi, 26 March 1926.

14 N. M. Goodman, *International Health Organizations and their Work* (London, 1952), 10–13.

15 LN Health R 880/28491, ILO letter of 4 Aug. 1920 and resolution concerning venereal diseases of 9 July 1920. R 815/5923, Rachel Crowdy to Secretary General, 19 Aug. 1920.

16 C. W. Hutt, *International Hygiene* (London, 1927), 134–8.

17 NCCVD/BSHC papers, Imperial and International Committee, 11 Oct. 1932, 3 Oct. 1933.

18 *BSHC Twentieth Annual Report (1932–1935)*, concerning 1936 recommendations by the ILO Sub-committee on Seamen's Welfare in Ports.

19 F. Mort, *Dangerous Sexualities. Medico-Moral Politics in England since 1830* (London, 1987), 199–200.

20 NCCVD, Minutes of the Services Committee, 26 Sept. 1921, 24 Oct. 1921.

21 NCCVD, Minutes of the Services Committee, 24 Oct 1921, 23 Jan 1922.

22 NCCVD/BSHC papers, Imperial and International Questions Committee, 20 Nov. 1923, 106–7, 15 Jan. 1924, 117, 19 Feb. 1924, 124, 30 Sept. 1924, 167, concerning leisure and social hygiene; 1 Oct. 1926 disagreeing that transmission of STDs should be a criminal offence; 13 Dec. 1926 concerning the International Labour Conference in 1927; 7 June 1934 concerning the 1935 International Labour Conference.

23 LN Health 12B, Doc. 27351 doss. 5923, G. S. Buchanan to Rajchman, 29 March 1923.

24 'Union Internationale contre le Péril Vénérien', *Health and Empire*, 2 (1923–4), 34–6.

25 H. C. King, 'The Paris Congress', *Health and Empire*, 2 (1923), 19–21; NCCVD/BSHC papers, Executive Committee, 3 Dec. 1923, 34–6. Imperial and International Questions Committee, 20 Nov. 1923, 107, 16 Jan. 1924, 114, 19 Feb. 1924, 123, 18 March 1924, 131.

26 ILO HY 1000/4/7–13 UIPV, Resolutions adoptées par le conseil de Direction, 9 Oct. 1925 (typescript). LN Health 12B/27351/5923, W. Snow to C. Hill, letter of 4 Aug. 1925, C. Hill to W. Snow, letter of 27 Aug. 1925. NCCVD/BSHC papers, Imperial and International Questions Committee, 20 Feb. 1925, 190, 17 March 1925, 197–8, 10 Sept. 1925, 224–5, 14 Dec. 1927, concerning Snow's report on the UIPV; 11 Jan. 1928, concerning BSHC and SPVD representation.

27 For French policies on STDs, see W. H. Schneider, *Quality and Quantity. The Quest for Biological Regeneration in Twentieth-Century France* (Cambridge, 1990), 146–69, 270–1.

28 NCCVD/BSHC papers, Imperial and International Committee, 3 April 1928.

29 ILO HY 1000/4/7–13 UIPV, Comité executatif, 9 Dec. 1928.

30 Quétel, *Syphilis*, p. 181. *BSHC Tenth Annual Report June 1924–June 1925*, 16–17.

31 NCCVD/BSHC papers, Imperial and International Committee, 22 June 1927, 10 Dec. 1928, concerning joint UIPV and LRCS representation to the ILO.

32 NCCVD/BSHC papers, Imperial and International Questions Committee, 30 Sept. 1924, 166.

33 NCCVD/BSHC papers, Imperial and International Questions Committee, 30 Sept. 1924, 162, 1 Oct. 1926, concerning an interview with Dr Knack on the non-regulation of prostitution; 31 Oct. 1928, concerning a meeting with the Hamburg MOH.

34 S. Neville-Rolfe, *Social Hygiene in the Mercantile Marine – the Brussels Agreement, a Survey of Action Taken from 1920 to 1934* (London, 1934). NCCVD/BSHC papers, Imperial and International Committee, 3 Apr. 1928, 18 Apr. 1928, 13 June 1928, 11 Oct. 1932, 16 July 1936, concerning the International Conference on the Welfare of the Mercantile Marine.

35 L. Cavaillon, *Les Législations antivénériennes dans le monde* (Paris, 1931). A second edition was issued in 1948.

36 S. Neville-Rolfe, *Social Biology and Welfare* (London, 1949), 261–4.

37 M. Hodann, *History of Modern Morals* (London, 1937), 99–100.

38 'Programme adopted at the first meeting of the UIPV. 27–28 January 1923', in NCCVD, Minutes of the Executive Committee (20 July 1922–7 Jan. 1923), 70, meeting on 7 Feb. 1923.

39 UIPV, resolution of 28 May 1928.

40 Hodann, *History of Modern Morals*, 103.

41 Hutt, *International Hygiene*, 138–46.

42 *League of Nations. Ten Years of World Co-operation* (Geneva, 1930), 289–96.

43 *Ibid.*, 296–7.

44 *International Conference on the Standardisation of Sera and Serological Tests* (London, 1921). *Second International Conference on the Standardisation of Sera and Serological Tests* (Geneva, 1922). *Investigations of the Serodiagnosis of Syphilis; Report of the Technical Laboratory Conference (Held at Copenhagen 1923)* (Geneva, 1924). *Report of the 2nd Laboratory Conference on the Sero-diagnosis of Syphilis held at Copenhagen* (Geneva, 1928). *Report of the 3rd Laboratory Conference on the Sero-diagnosis of Syphilis Convened at Montevideo* (Geneva, 1931). *Report on the Meeting of Experts on Syphilis and Cognate Subjects* (Geneva, 1928). *Progress of the Enquiry into Treatment of Syphilis* (Geneva, 1930).

45 *Sixteenth Session* (December 1930).

46 ILO N 102/4/2/0, Enquiry into the Effects of Family Allowances on the Physical and Moral Wellbeing of Children and their Birthrate and Mortality.

47 R. Symonds and M. Carder, *The United Nations and the Population Question 1945–1970* (London, 1973), 12–15.

48 M. Sanger (ed.), *Proceedings of the World Population Conference Held at the Salle Centrale, Geneva, August 29th to September 3rd, 1927* (London, 1927).

49 Symonds and Carder, *The United Nations*, 25–9.

50 For the SPVD, see Towers, 'Venereal disease', 80–7 and R. Davenport-Hines, *Sex, Death and Punishment. Attitudes to Sexuality in Britain since the Renaissance* (London, 1990).

51 Bayly, however, was a right-wing campaigner for Nordic racial purity, see Davenport-Hines, *Sex, Death and Punishment*, 239.

52 H. Wansy Bayly, 'Sexual reform and the prevention of venereal disease', in N. Haire (ed.), *The Sexual Reform Congress. London. 8.–14.:IX:1929* (London, 1930), 242–8. On the impact of Bayly's speech, see Hodann, *History of Modern Morals*, 88, 91, 93.

53 H. E. Sigerist, *Socialised Medicine in the Soviet Union* (London, 1937), 241–51.

54 Hodann, *History of Modern Morals*, 109–13.

55 The UIPV was a precursor of the IUVDT (the International Union against VD and Trepanatides).

56 'International Control of Venereal Disease. Excerpts from the Report on the Second Session of the Expert Committee on Venereal Diseases', *Bulletin of the World Health Organisation*, 2 (1949), 139–54.

57 Symonds and Carder, *The United Nations*, 58–66.

58 *The Second Ten Years of the World Health Organisation 1958–1967* (Geneva, 1968), 120.

59 S. P. Johnson, *World Population and the United Nations. Challenge and Response* (Cambridge, 1987).

60 *The First Ten Years of the World Health Organisation* (Geneva, 1958). *The Second Ten Years of the World Health Organisation*, 120.

61 WHO, *AIDS: Prevention and Control: Invited Presentations and Papers for the World Summit of Ministers of Health on Programmes for AIDS Prevention* (Oxford, 1988).

62 For these themes in a British context, see Mort, *Dangerous Sexualities*, 167, 175.

6

Hepatitis B as a model (and anti-model) for AIDS

WILLIAM MURASKIN

In the 1970s, a decade before AIDS became epidemic, it was discovered that a hepatitis B (HB) pandemic existed. Hepatitis B, often referred to as serum, or transfusion hepatitis, had been thought to be an iatrogenic disease, caused by western medical technology, and of limited spread outside the developed world. Due to the work of the geneticist Baruch Blumberg, an antigen associated with hepatitis B (the so-called Australian antigen) was accidentally discovered, and from that discovery a blood test for the virus developed. With the aid of the test, it was found that hepatitis B was the most widespread viral disease in the world, infecting billions of people, especially in Asia and sub-Sahara Africa. It was also discovered that between 200,000,000 and 300,000,000 people were chronic carriers of the disease and constituted an infectious reservoir for the virus. In some Asian countries, such as Vietnam, fully 15–20% of the population were carriers of the disease.[1]

In addition, researchers discovered that chronic hepatitis B infection was highly associated with the development of liver cancer; hepatitis B being a necessary (though not sufficient) cause of most of the world's liver cancer; and, in turn, liver cancer was the most frequent cancer in developing countries. Chronic carriership was also correlated with cirrhosis of the liver; most cirrhosis being caused by HB infection, not alcohol consumption. While hepatitis B infection in the developing world takes place at birth or during childhood, the fatal effects of the disease usually appear only in later decades, after the carrier has become a productive member of society; thus its economic effects on the developing world are more extreme than if it directly increased childhood mortality. It was estimated that approximately 25% of the carriers would ultimately die of HB-related illness (i.e. 15% of the females, but fully 40% of the males). This translates into 1–2 million deaths a year.[2]

The United States, along with western Europe, became designated as an area of low endemicity for hepatitis B. However, that status was not incompatible with 200,000 cases per year, an estimated 1,000,000 chronic carriers and 5,000 deaths.

Epidemiological studies revealed that hepatitis B in America was a disease contracted in adulthood rather than childhood, and that it was usually spread through sex, blood exposure and drug use. It could, however, be spread, as it was in Asia and Africa, from mother to child, or from child to child.

Dozens of identifiable groups were found to be at heightened risk of hepatitis exposure: health care workers, especially those intimately involved with blood such as heart and oral surgeons, dialysis workers, dentists, laboratory researchers, pathologists, emergency room nurses; morticians; institutionalised children with Down's Syndrome; multi-partner heterosexuals; gays and bisexuals; intravenous (IV) drug users; immigrants from Asia and sub-Sahara Africa; poor blacks; soldiers stationed in endemic areas (e.g. Vietnam and the Mediterranean); overseas travellers; Eskimos; American Indians; immigrants from Latin America; recipients of blood transfusions, etc. In addition, 40% of the cases fell outside any known risk group.

The hepatitis studies done in the 1970s made it possible for perceptive medical observers in the early 1980s to hypothesise the existence of a viral agent behind the appearance of immune deficiency related disorders spreading through the nation, since the cases were following the hepatitis B transmission routes: sex (gays), drugs (IV drug users), blood (haemophiliacs and transfusion recipients), and perinatal exposure (infants). With hepatitis B as a guide it was possible to devise, very early in the epidemic, effective guidelines for prevention of HIV infection. The recommendation to avoid sharing 'bodily fluids' came directly out of hepatitis B research. Indeed, some of the recommendations may have been overly restrictive (i.e. those dealing with oral sex) because of the power of the hepatitis B model.

While the two diseases are very similar in their manner of spread there are, nevertheless, vital differences. Hepatitis B virus is far more contagious than HIV. The amount of active virus concentrated in even tiny amounts of HB-contaminated blood is astronomical. It is a uniquely hearty virus that resists all but the most determined attempts at disinfection. It can survive for extended periods outside the body on environmental surfaces. Most importantly, hepatitis B, unlike HIV, can be spread 'casually', through rough non-sexual bodily contact (children's sports), by inanimate objects (e.g. towels, haircut scissors, ear-piercing stakes, tattooing needles, shared food that injures the gums – hard candy, or fruit) and insects (e.g. bedbugs). While the chances of infection from a single needle prick exposure to HIV is 1 in 100, for HB it is closer to 1 in 4.

One of the most important similarities between the two viruses is that they can be carried silently for years without the development of overt symptoms or warnings of potential infectiousness. The existence of this carrier state has created for both 'diseases' a whole series of major political, social, economic and moral problems. Both conditions raise the question of how to protect simultaneously the public's health and the rights of the infected. All the social problems faced by people with HIV in the 1980s were relevant for HB carriers during the previous decade. However, while HB served as a useful, indeed life-saving, model for understanding HIV transmission, it did not serve a similar role in raising and settling the social and moral problems surrounding chronic carriership. While useful scientific lessons were learned from the HB experience, humane and responsible social lessons were not. A major opportunity to create a model designed to balance equitably both the rights and obligations of the individual and the community was lost. Hepatitis B, more than AIDS, offered such an opportunity because the disease was usually not fatal, and it struck a far larger, more diversified and less stigmatised population – ranging from the family dentist to the troops stationed overseas.

Thus, in a crucial way, hepatitis B did not function as a model for AIDS. The failure to confront adequately the issues of disease carriership in the 1970s made it harder and more costly to deal with it in the 1980s. In addition, not facing and resolving the social and moral problems surrounding asymptomatic carriership was an important factor in frustrating efforts to curb the hepatitis B epidemic, despite the rapid development of a safe and effective vaccine. Indeed, in the years after the licensing of the vaccine (1982) the number of cases in the United States, instead of declining, soared from 200,000 to 300,000 cases a year.

In this paper we will look at why the hepatitis B carriers and the problems they raised were not adequately dealt with, and why no usable model for dealing with HIV carriers was in place when the second epidemic struck. Of especial importance will be the fact that HB was kept a low profile disease during the 1970s and 80s, and attempts to curb it were conducted outside public awareness. This lack of publicity and public debate did provide a limited number of benefits, but only at the cost of reduced disease prevention and the failure to generate solutions that would desperately be needed during the AIDS epidemic.

The early results of the hepatitis B epidemiological investigations painted an increasingly frightening picture of transmission. The disease seemed spreadable by countless everyday routes. The medical detective work tracking this was inspiring, but the implications were horrendous. In one case, cross-country runners passed through sticker bushes; a lead runner cut himself and left a small amount of blood on the sharp point of the sticker. The runners who came after him were cut on the same point and were infected because the lead runner was an asymptomatic HB carrier. In another case, poor children shared the same chewing gum. When one child was finished with it he stuck it to a bed post where the other children could pick it up and re-chew it. Hepatitis B virus was passed from child to child via the gum. In a third study, clerical workers were found to be infected with HB as a result of paper cuts they received while working with computer cards contaminated with minute amounts of blood. Numerous studies showed HB virus hidden on environmental surfaces in many hospital settings, and in dental offices as well. It looked like transmission might be uncontrollable.[3]

The research also started to identify groups at heightened risk of infection and carriership. One of those groups was health care workers.[4] Indeed, one piece of evidence that convinced Blumberg that the 'Australian antigen' he discovered was related to hepatitis B was that after one of his laboratory assistants was accidentally infected by hepatitis B blood, her serum converted from 'Australian antigen' negative to positive. In many medical fields the chances of infection with HB were overwhelming. Dentists over time had better than a 30% chance of being infected. Cardiovascular surgeons had rates of 50%, and pathologists even higher.[5] It was estimated that health care workers as a group had a 1% chance of becoming chronic carriers – and even higher in a number of specialities. The question arose, could, and would, health care workers infect their patients. To the dismay of many, a number of spectacular cases were discovered in which dentists or oral surgeons infected scores of clients; in one case more than fifty.

What should be done? At this time there was no vaccine, and special hepatitis B immune globulin (HBIG) was in very short supply, prohibitively expensive and only provided temporary protection. Stories of nurses and doctors being forced to leave hospitals when they were accidentally discovered to be carriers were becoming frequent.

A spectre haunted medicine, or at least the most aware members of the professions: the health care worker carrier as 'leper'. Indeed, the *New England Journal of Medicine* editorialised against the creation of a whole new leper class; as did Nobel Laureate Blumberg in a series of emotionally moving speeches and articles. The initial danger came from within the health care sector itself, especially from hospital administrators and clinical laboratory directors. The situation as it existed in the early 1970s was put very clearly by James Mosley:

> As soon as a relationship was recognized between the then recently described Australia antigen and viral hepatitis, it was found that health-care personnel, as a result of their occupation, had not only a greater risk of disease than most segments of the general population, but also a higher relative frequency of the carrier state . . . In view of the emphasis at the time upon what was called 'non-parenteral' transmission, concern was caused by [a] . . . report that a nurse . . . was associated with 11 cases for whom she provided care on a surgical ward . . . other reports of nonpercutaneous transmission . . . were being mentioned anecdotally. This circumstance . . . created an emotional climate in which there was serious discussion of HBsAG [HB antigen] testing of all health-care personnel, and prohibiting those who were positive from having further association with patients. There was even a proposal that persons contemplating a career in health care be tested before they enter professional training.[6]

But an even greater future danger existed: public panic and witch-hunting of the problem of hepatitis B carriers became a high profile issue. If the public became anxious about the health status of its doctors, nurses and dentists, carriers might be driven out of their professions in substantial numbers. And even the uninfected would live under the shadow of future HB exposure, potential carriership and occupational catastrophe. The fear of public panic and negative action continued throughout the 1970s, and into the 80s. In 1981, Mosley put it this way:

> Public concern about viral hepatitis as a menace to its health has continued to increase, and legal action, even if unjustified, would probably be pursued by any patient who did develop symptoms [from a health care worker carrier]. At present, our system of detecting persons with easily communicated hepatitis B infection is surveillance of all cases of viral hepatitis uncovered by routine morbidity reporting. Most states utilize follow-up [that] . . . inquires about antecedent medical, surgical, and dental procedures . . . How long this system of *post facto* identification of [medical personnel] communicable carriers will be accepted by the public is difficult to say . . . we may expect increasing pressure to do something.[7]

The position ultimately taken by the medical research establishment, and supporting public health agencies, was presented as early as 1971 by two eminent medical scientists, Harvey Alter and Thomas Chalmers: 'The implications of removing trained professionals from patient contact is too broad, the number too great, and the psychosocial cost too devastating to base decisions on anything but conclusive data.'[8] As a result it became common to play down the danger until that 'conclusive' evidence was produced and in the interim assume the most favourable scenario, that health care worker carriers were not a major source of infection. Not a very conservative policy where the public's health and safety was concerned.

When Alter and Chalmers published an interesting but limited study that showed a low risk of health care worker infection, it was heralded by health professionals as 'proof' that the fears were groundless. It was cited in article after article as the justification for the developing official policy of 'benign neglect'. Medical people also took comfort in Baruch Blumberg's study of hepatitis in haemodialysis units, which showed that good hygienic technique alone could change a catastrophic area of infectiousness into a safe environment. Governmental statements insisted that good hygiene offered adequate protection for patients regardless of the status of the health care worker. They also advised that carrier education should focus as much on hygiene in private life as on hygiene in the workplace.

Unfortunately, the actual situation did not live up to the claims. Good hygiene, rubber gloves, masks and extra care in handling blood might indeed protect patient and worker alike, but no mechanism to assure good hygiene and technique or the wearing of protective gear was instituted. Dental association journals well into the 1980s were full of the laments that dentists would not wear gloves or protective clothing. In 1981 Mosely could report that hospital staff often flagrantly disregarded simple hygienic requirements to wash their hands after seeing each patient. And 'As far as laboratory workers are concerned, it is apparent from several of the reports about nosocomial HBV that casual handling of specimens, failure to comply with safety measures such as the wearing of gloves, poor work habits, and sloppiness have contributed heavily to the frequent acquisition of HBV infection.'[9] Good technique is not protective if it is not applied, though claims as to its (theoretical) efficacy could and did justify failures to devise other policies.

In theory, a determined research effort was supposed to be undertaken to produce the hard evidence necessary to demonstrate the existence (or non-existence) of a health care worker carrier danger. This effort, however, was severely handicapped. Powerful forces in the health field were opposed to any prospective studies that might uncover carrier infection of patients. Almost no hospital wanted studies that might lay it open to law suits. The major physician organisations forbade large-scale research testing of their members for signs of chronic carriership. Individual doctors would not co-operate with studies that might threaten their careers. Governmental policy (as reiterated by the National Research Council (NRC) and the Advisory Committee on Immunization Policy (ACIP) of the Public Health Service) promoted only voluntary testing, and then suggested nothing be done to carriers unless clear evidence of patient infection was uncovered; and, even then, only suggested that restrictive action 'might' be considered, rather than required.

During the 1970s and 80s a great deal of impressive research on hepatitis B and its spread were carried out. The Centers for Disease Control (CDC) scrupulously investigated every report of possible patient infection by health care workers. But in the absence of large-scale controlled prospective studies, evidence remained anecdotal, and the policy of assuming the best remained in place. Mosely's comment in 1981 retains much of its force today: 'Unfortunately, 10 years of discussion have not produced data that are likely to be considered conclusive.'[10]

In sum, key figures and groups in the medical community, first came up against the problem of the hepatitis B carrier in relationship to health care providers. They thus faced a severe conflict of interest. They were dedicated to protecting the public's health but they were also committed to protecting their colleagues and associates from occupational catastrophe. They chose, in a situation of doubt and uncertainty, to err, if necessary, on the side of protecting the health care workers rather than the public. As a result they claimed that good hygiene, careful technique and worker education, by themselves, were capable of solving the problem. That position, however, was not combined with an effective system to ensure that adequate levels of hygiene were in fact maintained or an effort to prove that careful technique actually delivered the infection protection claimed for it. While the medical authorities insisted that future research would provide conclusive proof that this policy was correct, they were unable, or unwilling, adequately to carry out that research, at least in part because of the fear that the policy would be proven inadequate.

Influential members of the medical community also decided to maintain the hepatitis B carrier problem as a low profile issue. They felt that public debate of such a sensitive matter would be unfortunate, and lead to needless social and economic stigma and discrimination. The problem could be best solved by health professionals and researchers working outside the glare of public scrutiny. As a result, for most of the 1970s and 80s hepatitis B remained a 'silent epidemic' as far as the American people were concerned. During the period, most educated people could not tell the difference between hepatitis B and A, nor were they aware of the existence of a hepatitis B epidemic raging in the United States.

The strategy originally formulated for health care worker carriers became the model for treating all hepatitis B carriers. The policy included: (1) no active search for carriers, (2) voluntary, not mandatory, testing, (3) support for education of carriers in good personal hygiene, (4) education of household contacts of carriers in ways to reduce their risk of infection, (5) concentration by public health authorities on high risk groups and (6) avoidance of general public education about hepatitis B.

The general position toward carriers taken by the NRC and the ACIP assumed that all carriers, just like the health care workers, could protect their social contacts if they learnt and practised good personal hygiene. The type of care required is well summarised in the following passage:

> A general list of do's and don'ts can be formulated for the carrier . . . The carrier should not share articles that could penetrate his/her skin or be contaminated with blood, such as razor blades, nail files and clippers, scissors, toothbrushes, and douche and enema equipment. A carrier should take care of his/her own abrasions and lacerations or seek medical attention. Blood contamination should be promptly cleaned, and soiled items disposed of or laundered. Skin breaks should be covered. The carrier must inform medical personnel of his/her status, and he/she must not donate blood . . . the carrier . . . [has] the responsibility of informing sexual partners of the risk of transmission of hepatitis B. Partners may agree on the use of a condom.[11]

This is rather important information for carriers and their contacts to possess. However, in the absence of programmes actively to locate and test possible carriers no such hygienic education could be given. Most carriers did not know they were infected; and their household contacts and sex partners had no way of knowing that they were at risk. Neither carriers nor contacts could learn or practise protective hygiene in such a situation. The policy sounded reasonable and potentially effective on paper, but was meaningless without some plan to find carriers. In fact, it could be only offered to the small fraction of carriers who were accidentally discovered through donations to blood banks or as a side effect of other medical testing. (Even in these cases, the blood banks and Red Cross did minimal carrier education – often only contacting them through the mails, and informing them of their status in language difficult for the lay person to comprehend.)[12]

While dozens of known high risk groups existed, medical and governmental agencies had links with almost none of them except for health care workers. Even small, easily notifiable groups like morticians were never contacted and warned of their high risk status. Many of the named groups, such as gays, bisexuals and IV drug users, were primarily secret groups whose actual memberships were unknown, and whose spouses and sexual contacts were unknowable.

Surprisingly, hospitals neglected to test in-coming patients for their hepatitis antigen status. On the face of it, hospital admissions offered an easy way to locate large numbers of carriers. Testing patients on entry would have offered both increased protection to hospital personnel and would have permitted extensive education of carriers and their household contacts about ways to prevent transmission. However, routine testing was not instituted. In the eyes of at least some medical participants, there was a tacit, 'social contract' involved: we (health care workers) will not test the public for carriers (and thus continue to accept a higher risk of hepatitis infection from patients) and the public in turn will not demand testing of medical personnel for carriership.

The failure to institute routine testing provided a clear answer to the three ethical dilemmas Baruch Blumberg saw raised by hepatitis B screening: 'How much biological knowledge about an individual should be divulged and subsequently permitted to impinge on their daily lives . . . [; s]hould routine screening of health personnel be mandatory . . . [; and s]hould we regulate the risks inherent in people living together?'[13] The lack of hospital testing was also in harmony with the general American way of handling such problems. As Blumberg put it: 'most infectious diseases are communicated from person-to-person; therefore, the most obvious way to avoid infection is isolate the carrier. Since the disadvantages to this are numerous, our society generally opts to risk exposure to a particular disease'.[14] The answer to almost all the problems created by carriership seemed to be to minimise knowledge and accept risks.

Such 'philosophical' views were reinforced by questions of cost and effectiveness:

> It has been suggested by some that patients newly admitted to hospital or newly accepted in dental practice might be pre-screened for HBsAg. Identified carriers of HBsAg would presumably be subject to the establishment of 'special' precautions for the handling of their clinical specimens. It is not yet clear, however, whether such identification of HBsAg carrier patients would result in any greater reduction of risk of HBV exposure than the scrupulous enforcement of procedures for the safe handling of *all* clinical specimens might provide. Given the extremely high cost of mass HBsAg screening of patients without concurrent knowledge of the benefits to be gained by such screening, introduction of this procedure presently cannot be recommended.[15]

The problem with the Blumberg approach was that since no one had informed the American people about the problems of hepatitis B carriership, the society had no opportunity to 'opt' for the risk of exposure to this particular disease. The cost and effectiveness argument, even if meritorious (and that is far from clear), totally ignored the stated public health goal of informing carriers of their status in order to educate them (and their household contacts) in ways to minimise transmission.

For many in the medical and public health communities, their real belief was that in the absence of a vaccine or effective treatment nothing could or should be done about carriers. They saw carrier hygienic education as of little value, and notification of hepatitis B surface antigen (HBsAG) positive status as psychologically traumatic and socially dangerous. But if one accepted that perception it radically undermined the standard justification for the low profile, minimal interventionist, high risk group oriented, hygiene and education strategy: that it could control the epidemic without more restrictive or intrusive measures.

The official policy was in fact, no-policy. As far as the carrier reservoir of infection went, nothing was being done. And instead of looking for legal and administrative solutions to the danger of unnecessary social and economic discrimination against carriers, the problem was avoided by simply not trying to find them.

The licensing of a safe and effective vaccine in 1982 promised to change the situation dramatically. While the vaccine had no direct therapeutic effect on carriers, it provided the means to stop the spread of the epidemic. It also made the necessity of finding carriers more urgent: now household and sexual contacts could be protected by vaccination, not just education in hygienic procedures.

Unfortunately, the hoped for benefits from the vaccine were not realised. The epidemic was not only not stopped, but in the years after the vaccine's development it spread with increased vigour. By the mid-1980s the number of cases had escalated from 200,000 to 300,000 a year. This spectacular increase occurred despite the increasingly successful control of the epidemic among homosexuals, the largest risk group. The adoption of 'safe sex' practices by gay and bisexual men brought about by the AIDS epidemic offered protection not only against HIV, but also against HB infection. Before 'safe sex', 80% of gay men were exposed to hepatitis B infection within the first few years of initiating sexual activity; and the chronic carrier rate among gays was between 6% and 10%. Death from hepatitis B related illness was a significant cause of mortality in the gay community. After the safe sex campaign, gay exposure and illness dropped dramatically.[16] However, multi-partner, unprotected heterosexual transmission more than compensated for the drop among gays, and sexually active heterosexuals became the engine of the epidemic's intensification.[17]

The failure of the new vaccine to curb the epidemic was the result of a number of factors. The chief problem was its price. The vaccine required three separate shots, at a cost of $100 for adults, around half that for children. The administrative costs for the vaccine raised the consumer price considerably higher. The price came as a shock to the hepatitis research community. The fact that Saul Krugman had developed a proto-vaccine by simply boiling infected serum, and that Baruch Blumberg had patented his early vaccine work, made the astronomical price that much harder to understand. Unfortunately, Blumberg had discovered that the actual development of a practical vaccine required the aid of a major pharmaceutical company. And no one would co-operate without exclusive rights in various markets. Merck Sharpe & Dohme finally developed the vaccine but then possessed a monopoly in the United States. It was widely believed in public health circles that the price bore no relationship to developmental cost, but the drug companies guard their costs, as they do their lives. Recently, an independent study of hepatitis B production has shown that when the vaccine is produced in large quantities the unit price falls to as low as $0.10 a dose![18] For many years, public health officials hoped that when a DNA form of the vaccine was developed, and a second pharmaceutical firm entered the competition, the price would finally fall. However, when SmithKline entered the American market in the late 1980s, the consumer price rose to $170 for the adult series.

It could be argued that the price structure alone, especially in an era of governmental cut backs under both Carter and Reagan, doomed any successful use of the vaccine to end the epidemic. Many medical people believe that. But the situation was much more complex. First, the mind-set that dominated the pre-vaccine period continued to operate after the vaccine was developed. Fears concerning the problem of health care worker carriers continued. The vaccine did not solve the problem of patient infection from health care workers. Patients were unvaccinated and vulnerable. Thus, the danger of public hostility to health care worker carriers was still a real one even after 1982.

In the discussions surrounding the ACIP's recommendations for hepatitis vaccine usage, the question of the health care worker carriers and the occupational and social problems they faced were still of great importance. The ACIP

> carrier[ship] is not known . . . no routine system exists in most States for reporting an HBV carrier identified as part of such medical studies . . . Only a small proportion of the estimated 12,000 new HBV carriers which result from infections each year in the U.S. are identified, and an even smaller proportion of those identified are reported to public health units . . . [A]nnual births in the U.S. include a minimum 10,000 babies born to HBV carrier mothers. Very few of these carrier mothers are currently being identified . . . Some refugee clinics in the U.S. have tested for HBV carriers, but this has not been a uniform practice in most clinics. No Statewide or national registry of these identified HBV carriers exists.[19]

The author went on to say that because of the high cost of the vaccine 'consideration must be given' to only administering it to individuals in high risk groups; however, he explicitly pointed out that 'Screening only the known high-risk groups will not identify the vast majority of HBV carriers.'

The draft went on to spell out succinctly the basic problem for dealing with carriership:

> Aside from those programs whose specific objective is to identify HBV carriers, such as the blood donor and prenatal screening programs, there is no agreement that other programs which potentially could identify HBV carriers should or will do so. HBV carriers should be identified in order to assess an individual's medical prognosis and risk of transmission of infection to others. However, from the standpoint of ethical and legal issues regarding patient confidentiality, and the potential need to restrict carriers from entering some types of employment, many facilities and individuals would prefer that HBV carriers not be identified.[20]

The document recommends carrier education for those (few) carriers who are identified.

This draft of the recommendation proposed no solution to the carrier problem. It certainly did not call for new aggressive programmes to find carriers, to educate them and to vaccinate their contacts. In that respect it was not a break with the past consensus. But, by its candour, and openness, it clearly revealed how extensive the problem was, and how insufficient current policies were. It simultaneously accepted the status quo as it laid the groundwork for undermining it.

These comments were not included in the final document. Rather, like previous reports, the recommendations gave the impression that education, and now vaccination, would be available to carriers (in general) and their contacts, and thus could achieve control of the epidemic.

The CDC's hepatitis people were also in the minority on the problem of vaccination of health care workers in the hospitals.[21] Their position of protection of health care workers with blood contact was quite aggressive: all of them should be offered vaccine. The hospitals were vehemently opposed to such a recommendation. Cost, not control of the epidemic, was their primary concern. The ACIP received many letters that made the hospitals' position quite clear: 'As you probably know, the proposed recommendations of the [ACIP] . . . appear to be quite broad, and would include most (if not all) hospital workers. Many of our hospitals have limited financial resources . . . Indeed, for many hospitals the financial resources may never permit the immunization of all hospital employees.'[22] Another one said: 'members of the Society of Hospital Epidemiologists of America who are fearful that CDC Phoenix [the hepatitis research centre] will promulgate vaccination recommendations which might not be appropriate for their situation and might be extremely burdensome financially.'[23] Robert Haley, Director of Hospital Infections Program, CDC, reassured those anxious about the forthcoming recommendations that their views were well represented by people sitting on the ACIP, which they certainly were.[24]

The position taken by the ACIP was very responsive to the hospitals. So responsive, that it drew a fierce letter of outrage from the distinguished hepatitis expert Jules Dienstag:

> one of the sentences [in the latest draft] . . . is quite ill-conceived: 'Since the risk of hospital personnel acquiring hepatitis B varies . . . among hospitals . . . , each individual hospital should formulate its own specific immunization strategy' . . . It appears that at least certain Committee members were more concerned with 'protecting' hospitals from the costs of vaccination than with protecting health care personnel . . . The role of the APIC should be, instead, to foster the prevention of hepatitis B infection; anything short of a strong statement will provide hospitals with an excuse to avoid involvement in vaccination programs for their employees at risk.

He went on to say,

> In bending over backwards not to commit hospitals with ostensibly lower risk of hepatitis, the APIC will have done an immeasurable disservice to hospitals with substantial . . . risks. Moreover, it is rather debatable that *any* hospital has a low hepatitis risk . . . I cannot stress enough how detrimental the impact of the current version of the recommendations would be; its most unfortunate effect would be to interfere with vaccination of the one group for whom the vaccine was originally intended and upon whom its impact would be the most profound.[25]

(It is interesting to note that Dienstag, who had been requested by the ACIP to write up an outline dealing with 'the vexing legal and ethical dilemmas physicians, hospital administrators, and public health officials will' confront because of the vaccine, focused exclusively on health care workers – even going so far as to assume that the vaccine was designed primarily for them. This narrowness of vision, in a very thoughtful observer, was typical of the pre- and post-vaccine period.)

The hospitals were not only afraid of the cost of vaccinating their employees, but they were afraid of other financial dangers as well:

> How does vaccine availability affect the liability of a hospital or health care provider when . . . a health provider transmits hepatitis B to a patient. Presumably, availability of the vaccine and its administration to health care personnel will increase the visibility of the problem of hepatitis B health care workers to the general public. This in turn might lead to an increase in the number of lawsuits by patients who have acquired or who suspect they acquired hepatitis B from their physician or other health provider . . . theoretically liability could be increased by the availability of vaccine; the hospital [can] . . . prevent hepatitis B with vaccine. Not having done so, would their liability be even higher?[26]

Fear of public awareness of the carrier issue continued to remain a potent influence on policy.

The final ACIP document adopted a 'high risk strategy' for curbing the hepatitis B epidemic. The strategy was aimed exclusively at 'Persons at substantial risk of HBV infection who are demonstrated or judged likely to be susceptible.'[27] The recommendations did not recognise obstacles in carrying out that policy except in so far as it allowed the hospitals to decide their own needs. The adoption of such a policy was strongly affected by the cost of the vaccine. With a limited supply, and a prohibitively high price, one had to choose targets carefully. Nevertheless, here as elsewhere, the pressures for this strategy were not purely economic. The high risk group emphasis kept the epidemic out of public consciousness and supported the low profile approach. It treated the epidemic as if it could be controlled by closely focused public health work without the larger society's involvement.

On the face of it, the high risk emphasis was from its inception fatally flawed. First, 40% of all cases of HB were among people in no assignable risk group. Second, the largest risk groups (IV drug users, married bisexuals, gays not out of the closet) were hidden and largely unreachable through low visibility channels. (Public health authorities often lacked broad or deep links even to the highly visible, organised gay community.)[28] Third, since carriers generally were not actively searched for, there was no way to find, let alone vaccinate, household and sexual contacts of hepatitis B virus (HBV) carriers. Even in theory, the epidemic could not be controlled when people at risk could not be adequately identified, educated and vaccinated.

On a visit to the Hepatitis Branch of the CDC in 1990 I asked why such a no-win policy was adopted. I was told that it was generally believed in the Branch that it was an unworkable approach from the start. The Branch had to prove to its numerous constituencies (e.g. ACIP, State Epidemiologists, Medical Professional Associations) 'the Null Hypothesis'.[29] It had to amass facts and figures that demonstrated that a narrowly focused high risk strategy was not practical. This is exactly what was done as the epidemic inexorably spread in the years after the licensing of the vaccine.

The hepatitis people said that in 1982 there was no support for the obvious alternative to a high risk strategy: universal child and adolescent vaccination. The reasons for the lack of support were many. First, the cost would be astronomical; and who would pay for it? The manufacturer had a stranglehold on the vaccine in the United States and severely limited the possibilities. Hepatitis Branch researchers continually raised the question of lowering the price with representatives of the company, but found they were hitting their heads against a stone wall. In addition, their best contacts at Merck were primarily with fellow scientists who were 'outside the loop' of price determination. Second, in the eyes of many public health officials outside of CDC, Atlanta, hepatitis B was not perceived as a national problem at all. It was seen as a problem of the east and west coasts, and of limited groups in those areas. Also, for many such observers, HB was pigeonholed as a sexually transmitted disease (STD), primarily striking stigmatised and unpopular populations. Such a label was the kiss of death in much of the country. Those people were 'not found in our states'. No political leaders on the local level would provide money for protecting such people; and state public health authorities would not ask them to.[30] Third, most medical personnel were generally ignorant about the full extent of the epidemic, or who in the larger population was at risk, or even the many ways the virus was transmitted.[31] What the Branch had to do was collect its data and then slowly win over the key groups that were seen as forming its natural audience – medical and public health organisations.[32]

For years, the scientists and public health officials at the Centers for Disease Control worked tirelessly to overcome the many external hindrances to an effective hepatitis B programme in the United States.[33] However, the Hepatitis Branch members tended to be unaware of their own involvement in creating or supporting some of the problems that frustrated them. There was less inevitability about many of the obstacles they faced than they realised.

Most of the problems that prevented the Branch from recommending to the ACIP a more adequate approach to curbing the epidemic stemmed directly from the long-established tradition of avoiding publicity about hepatitis B. As a result, there was no public agitation, or even knowledge, about the epidemic. Thus, there was no mass support for raising money or creating mechanisms to do anything about it. Since there was no public concern, there was no public outrage at the high cost of the vaccine or the quasi-monopoly that Merck had obtained for itself. People did not know, and therefore did not care. While most hepatitis B was indeed sexually transmitted, and stigmatised groups were indeed numerically the likeliest victims, it was not inevitable that the disease would be socially constructed as an STD. It was a disease that almost anyone could come into contact with: in the hospital through transfusion (even after the blood test was developed), in the armed forces, as a traveller overseas to endemic areas, from one's dentist, or surgeon; from an ear-piercing, a tattoo, a haircut. The groups affected included one's local mortician, the neighbour's retarded child, the Latin immigrant down the block, the waiter at the local Chinese restaurant, the Korean or Vietnamese orphan adopted by a prominent church member, the business man at his yearly convention, the college student on a Saturday night. There was nothing that required the disease to be perceived by local public health authorities or anyone else as simply an STD suffered by 'Them'. Of course, it would have required a major public educational effort to provide an alternative image of the disease's victims.

The hepatitis people at CDC did not think of themselves as having such a public educational role. They were not trained for such a function. They also did not think to search out non-medical organisations that might share their goal of a more sweeping strategy.[34] Quite revealing is an incident that occurred in 1990. In that year, the Occupational, Safety and Health Administration (OSHA) made known that it planned to issue guidelines that required all employers of workers who came into contact with blood to offer hepatitis B vaccination free of charge to its workers. That would have included millions of health care workers, as well as policemen, firemen, sanitation and urban park workers. It was a great victory in the eyes of the Hepatitis Branch people for a more comprehensive and effective policy; they had never been about allowing the hospitals to determine their own vaccination needs. What they did not realise was the role played by the Service Employees International Union (SEIU) in the announcement. The union had been relentlessly pressuring OSHA for years to issue guidelines to protect workers, going so far as to threaten OSHA with a court law suit if they were not issued.[35] Significantly, the union had discovered that fears about hepatitis B infection were a top concern of its large health care worker membership. The union had for years fruitlessly tried to make contact with people at the Centers for Disease Control, asking to be included in 'the information loop' in connection with hepatitis B (and AIDS). They received no positive response. The CDC as a whole, not just the Hepatitis Branch, was not oriented to deal with the non-medical public. They did not think of such people as a major resource. More commonly, when the public was thought about, it was perceived as a threat to rational public health policy.

The Hepatitis Branch people had, like everyone else who was knowledgeable about hepatitis B, been opposed to public debate for fear of the negative social/occupation effects it would create for chronic carriers. This orientation becomes exceptionally clear in their handling of the problem of Asian immigrant and refugee hepatitis carriers.

While most of the discussion of the dangers of discrimination and stigma against carriers in the medical and public health literature focused overwhelmingly on health care workers, there had always been concern about foreign carriers entering the United States, especially from Asia.

The issue surfaced very early in the 1970s:

> A particular difficult issue arose in respect to adoption of children from Vietnam. Many orphans had been brought to the United States and placed for adoption. What if these children had been screened and some of them found to be carriers? Would this affect their chance of adoption? Would a single blood test determine the fate of a young child? The Public Health Service decided not to test these orphans for HBV as a condition of entry.[36]

The problem was also acute for non-Vietnamese orphans. Most foreign adopted children in the United States come from Korea, another country with high carrier rates. If screening children as a condition of entry was undesirable on humanitarian grounds, so was informing would-be adoptive parents: 'Should such identification deter adoption? . . . consider the plight of potentially adoptive parents who see 10 or 15 children available for adoption and then are told that one or two of them may carry hepatitis. That finding alone could deter prospective parents.'[37] Ultimately, a system was set up in the United States that made notification of would-be adoptive parents of the HBsAg status of their child very unlikely. Except in the case of South-East Asian refugees, the government never got involved in testing orphans outside the United States. For example, there was no programme to test orphans from the major donor nation, Korea. When the American government decided to test 'unaccompanied minors' in the South-East Asian refugee camps, there was no procedure to pass that information on directly to prospective parents. The decision to notify was left up to the private philanthropic organisations that sponsored adoption – groups that were reluctant to undermine the adoption process. While CDC policy recommended the vaccination of adoptive family household members, it was emphatic that carrier adoption should not be dependent on or delayed until the household was vaccinated; but since many (probably most) families were never informed of the hepatitis carrier problem, family vaccination often never occurred.

The Hepatitis Branch itself became deeply involved in the question of discrimination against Asian carrier children. As the number of Asians radically increased in the United States, so did the number of carriers. Indeed, at one point two-thirds of all new carriers added to the American population came from immigrants – primarily from Asia.[38] A significant public health question arose around the question of carriers in day care facilities. There was much evidence that horizontal transmission, especially among toddlers, was a major form of transmission, especially in unsanitary situations. Horizontal transmission was the overwhelming type of spread in Africa, and accounted for most infection even in Asia where perinatal transmission was common. The possibility existed that in home-like conditions, such as day care or nursery school, similar infection could occur.

The Hepatitis Branch received many inquiries from day care centre directors about the question of infection-risk.[39] The Branch emphatically informed the directors that there was no problem, that with good hygiene, and a little extra care, there was little or no danger of contagion. The rules for good hygiene were easily spelled out:

> Specific hygienic standards should be maintained in all settings involving close contact between an HBV carrier child and other persons for an extended period of time. The implementation of such standards by supervising adults is most important in settings in which contacts are unvaccinated and carriers are too young to adhere reliably to personal hygienic standards . . . In general the carrier child should be discouraged from placing others' fingers in his/her mouth or his/her own fingers in others' mouth, sharing food and mouthing objects that other might use. Attempts should be made to curtail aggressive behavior such as biting and scratching . . . Open skin lesions of carriers and contacts should be covered. Items soiled by the carrier's blood or saliva should be either thoroughly cleaned by detergent and water before reuse or discarded . . . Blood-contaminated objects and surfaces should be disinfected . . . Persons who clean up blood spills or dress wounds of carrier children should wear gloves.[40]

This was not an easy (or likely) regimen to be carried out in a day care centre. Not surprisingly the directors were not reassured, and rejected the carriers.

While the CDC recommended maintaining good hygiene for all carrier situations, they had extra recommendations for aggressive carriers. However, the CDC opposed testing children for carriership before acceptance or after admittance. The only way they would know about the presence of a carrier, especially an aggressive one, was to be voluntarily informed by the parent. However, parents usually did not know their child was a carrier. There was no immigrant testing programme. While there was a superb pregnant-refugee testing programme, it was concerned almost exclusively with identifying carrier mothers in order to vaccinate their newborns. It did have an interest in vaccinating susceptible household members – especially children, but it was not concerned with existing non-pregnant carriers. While there was no official policy concerning what to do after a child carrier was stumbled upon, refugee programme workers were unofficially told by the CDC not to pass carrier information on to schools and day care centres, for fear of stigmatising the child. The danger of discrimination against the children, and the larger groups from which they came, seemed much greater than any risk to uninfected children.

Unfortunately, the reassurances that the CDC gave day care centre directors was not based upon persuasive scientific studies. The data was not available to be sure how great the risk of toddler transmission actually was. There were excellent reasons why the proof was lacking – especially the problem of informed consent, which, by alerting the parents of susceptible children to the presence of a carrier, led to flight rather than co-operation. But the fact was that the proof was missing, the studies not done. Exaggerated CDC claims for the safety of integrating carriers into day care were based more on humanitarianism than scientific research.

In the late 1980s, a Hepatitis Branch study of Asian refugees living in Georgia documented significant horizontal transmission to children in households where a carrier was not present. This study showed that conditions similar to South-East Asia could be duplicated in the United States. On the basis of this finding ACIP recommended that all Asian children, below the age of five, immigrant as well as refugee, be vaccinated. However, neither the study nor the CDC raised the question of the implication of these unsettling finds to day care centres.

For the CDC the danger of discrimination against carrier children was a pressing moral problem. They saw the public (in this case, day care centre directors, and parents of susceptible children) as irrational about hepatitis B when they became aware of it. They responded (1) by claiming a greater level of safety for integrated settings than they could document; (2) by championing unrealistic levels of 'good hygiene' rather than expensive vaccination, as protection for the uninfected; (3) by rejecting the need for antigen testing; (4) by recommending that mothers of rejected carriers stop informing the directors and (5) by insisting that health workers who knew of refugee carrier children not pass that information on to the schools and centres.

Their motivation was humane and understandable. But they put the protection of carriers above the rights of the uninfected population, just as the medical community had always done with health care worker carriers. They also continued to support the traditional policy of shunning public discussion about the issue. What they did not realise was that the problem of hepatitis B among Asians presented opportunities not just dangers.

If the goal of the Hepatitis Branch was to build a constituency supportive of universal childhood vaccination against hepatitis B, and by the late 1980s that was their explicit goal, then the problem of Asian immigrants was more a potential asset than a liability. There exists a lot of goodwill in the United States for the Asian newcomers, and a significant amount of guilt for the South-East Asian refugees and orphans. The enlarged Asian presence in the United States has increased the drive to reconceptualise the country as a unique type of multiracial society. The existence of large-scale HB carriership, while threatening temporarily to increase racial prejudice and discrimination, provides a powerful rationale and impetus for universal childhood vaccination as a necessary (and affordable) investment in allowing America to live up to that evolving ideal. Open democratic controversy is not neat, or painless, and certainly has its risks, but it is the best hope for resolving issues of conflicting rights. Candidly dealing with the problem of Asian carriers, like health care worker carriers, has always presented the danger of stigma and discrimination but also the possibility of a creative debate leading to protective laws guaranteeing confidentiality, protection against job, housing and social harassment, and safeguards for preserving medical and insurance coverage.[41] Today, it also has the potential to provide moral support for large-scale vaccination. The immediate effect of publicity would probably be painful, the racists would come out of the woodwork, but the democratic process should not be jettisoned or undermined because of it, as it too often has been in the case of hepatitis B.

The negative results of not directly and publicly facing the moral and social problems surrounding the hepatitis carriers have been many. First, it has made it much harder successfully to fight the hepatitis epidemic. Without public concern and outrage, resources for the battle have been meagre and inadequate. People at risk were left in ignorance, hygienic safety procedures have been left uncommunicated and unenacted by those who needed to learn them. Second, the scientific miracle of a safe and effective vaccine has been subverted by a monopoly-dictated price, that the public did not know about and thus could not protest. Third, the medical and public health literature has been distorted by self-serving or humanitarian claims about carrier safety, that were premature or unwarranted as the medical community tried to protect health care workers, immigrants and others from the dangers of an uninformed and ignorant populace. Fourth, the public has been purposefully kept ignorant, and then placed at risk in vulnerable situations (from their dentist's office to their toddler's day care centre) without their consent or agreement; they could not 'opt for the risk', since they were not consulted.

In addition, it left the public unprepared for the social and ethical dilemmas surrounding HIV carriers during the AIDS epidemic. All of the AIDS social/ethical issues were relevant to HB carriers. Hepatitis B should have been the model for a humane, fair and responsible balancing of carrier rights and the public welfare. All of the problems that had to be dealt with from scratch in a climate of mortal fear and homophobia could have been already settled. The fact that hepatitis B was a less fatal disease than AIDS and potentially affected a much broader spectrum of the population made it a better disease over which to fight the issues of individual rights versus the public health. Thus, hepatitis B should have been both the transmission model and the social/ethical model for dealing with the issues surrounding asymptomatic disease carriers. Unfortunately much of that opportunity was lost – to the detriment of adequately dealing with both the hepatitis B and AIDS epidemics.[42]

Perhaps even more tragic, the hepatitis B epidemic demonstrated the existence of a series of infectious super 'highways'; transmission routes paved by major social, technological and cultural changes: increased medical innovations requiring significant exposure to blood, sexual revolution (straight and gay), large-scale recreational and addictive IV drug use and massive international travel. Looking at that new thoroughfare one could predict that other diseases would ultimately come rolling down it. What was needed was a series of road blocks. Widespread use of condoms was an obvious start. If hepatitis B had become the public issue it should have in the 1970s, anti-hepatitis B 'safe sex' could have conceivably been one result, and the AIDS blitzkrieg immobilised before it began. But it did not become a public issue, no one wanted to risk panic and hysteria, stigma and discrimination. Were the gains worth the losses? I do not believe they were.

NOTES

1 Documentation for most of the material in this chapter can be found in William Muraskin, 'The silent epidemic: the social, ethical, and medical problems surrounding the fight against hepatitis B', *Journal of Social History*, 22 (1988), 277–98; William Muraskin, 'Individual rights versus the public health: the controversy over the integration of retarded hepatitis B carriers into the New York City public school system', *Journal of the History of Medicine and Allied Sciences*, 24 (1990), 64–98; and William Muraskin, 'Individual rights vs. the public health: the problem of the Asian hepatitis carriers in America' (manuscript sent out to scholarly journals, April 1991). Additional references will be provided for material not found in those articles.

2 Ian Gust, 'Public health control of HBV: worldwide HBV vaccination programme', in John L. Gerin, Robert H. Purcell and Mario Rizzetto, *The Hepatitis Delta Virus* (New York, 1991), 333. When hepatitis B infection occurs at or near birth (a common situation in Asia) the chances of becoming a chronic carrier are exceptionally great. The risk of developing carriership from infection is very high throughout childhood, in adolescence and adulthood. In the west most infection occurs in the late teens and early 20s, with carrier rates varying from 1 to 10%, depending upon the risk group.

3 These studies discovered transmission routes, but could not quantify the risks involved; thus, they made transmission seem more likely than they turned out to be.

4 In the late 1980s, despite the fact that a large minority of health care workers had been vaccinated against HB, between 10,000–15,000 continued to be infected each year, with 300 dying as a result of the infection. See Baruch Blumberg, 'Feasibility of controlling or eradicating the hepatitis B virus', *American Journal of Medicine*, 87 (suppl. 3A) (1989), 3A–2S–4S.

5 Comments of James Maynard, in Wolf Szmuness, Harvey J. Alter and James Maynard, *Viral Hepatitis: 1981 Symposium* (Philadelphia, 1982), 309.

6 *Ibid.*, 555–6

7 *Ibid.*, 560.

8 *Ibid.*, 556.

9 *Ibid.*, 552.

10 *Ibid.*, 556.

11 Richard E. Sampliner, 'Follow-up and management of hepatitis B carriers', in Robert Gerety (ed.), *Hepatitis B* (New York, 1985), 167.

12 For example, when I was interviewing at the CDC in 1990 I saw such a Red Cross letter notifying a donor of his/her carrier status – the letter's message bordered on the unintelligible even to someone studying hepatitis. The receiver would have little reason to assume there was a major problem worth worrying about.

13 Baruch Blumberg, 'The bioethical dilemma of the hepatitis carrier', *P&S Journal*, 25–9 (Winter 1977), 27–8.

14 *Ibid.*, 28.

15 James Maynard, 'Viral hepatitis as an occupational hazard', in T. Oda (ed.), *Hepatitis Viruses* (Baltimore, 1978), 303.

16 See Mark Kane, Miriam J. Alter, Stephen C. Hadler and Harold S. Margolis, 'Hepatitis B infection in the United States', *American Journal of Medicine*, 87 (suppl. 3A) (1989), 3A–11S–20S, 3A–12S.

17 *Ibid.*, 3A–12S.

18 See Richard Mahoney, 'Cost of plasma-derived hepatitis B vaccine production', *Vaccine*, 8 (1990), 397–401.

19 Preliminary draft of ACIP recommendations, dated 14 May 1982, 16–19. Draft from J. Michael Lane to members of the committee. Found in ACIP files, CDC, Atlanta.

20 *Ibid.*, 20.

21 See *Hospital Employee Health*, 1, 7 (July 1982), in the files of the ACIP, which discusses the final document as a compromise between the ACIP and the CDC consultants to the committee.

22 Letter to Robert Haley, CDC, from John McGowan, Jr, President, Nonsocomial Infections Division, American Society for Microbiology, 31 March 1982, ACIP files.

23 Letter from Donald Goldman to Robert Haley, CDC, 30 March 1982. ACIP files.

24 Letter from Haley to George Counts, President-Elect of the Association for Practitioners of Infection Control, 4 May 1982, ACIP files.

25 Letter from Jules Dienstag to Michael Lane, 28 May 1982. ACIP files. Dienstag in other letters made clear that he, and Massachusetts General Hospital, recommended that health care workers at highest risk should be offered vaccine at the hospital's expense. He also said that 'in the best of all possible worlds, health care personnel would be vaccinated as they begin clinical training . . . but these educational institutions are even less likely to be able to afford the vaccine' than hospitals. See letter from Jules Dienstag to Michael Lane, 5 May 1982, ACIP files.

26 Letter from Jules Dienstag to Michael Lane, 7 May 1982, ACIP files.

27 *Morbidity and Mortality Weekly Report*, 31, 24 (25 June 1982), 317–22, 327–8.

28 There were attempts to communicate with the gay community. David Ostrow, founder of the Howard Brown Memorial Clinic in Chicago and a leading gay medical leader, helped organise a 'Task Force on Vaccination Strategies for Sexually Transmitted hepatitis B Virus Infection' that included Bruce Dull of the CDC, Saul Krugman of New York University, Cladd Stevens of the New York Blood Center, and a number of CDC Resource Personnel. There was a bridge between gay medical activists and the CDC. That group also prepared a paper for inclusion in the ACIP recommendations that called for important outreach programmes aimed at the gay community: 'Specifically, all school health education programs should communicate to their students the high risks of HBV infection that will be experienced by homosexually active males. In addition, college and community organizations of homosexually active persons and public health departments and clinics should make special efforts to identify high risk individuals

and encourage them to seek serologic testing. Publicity and educational programs should include a full variety of approaches such as special publications, leaflets, posters, and the gay media, and may be developed cooperatively with plasma collection centers and the vaccine manufacturer' (*Homosexual Health Report*, 1, 2 (1982), 25, found in ACIP documents). It sounded like a good approach, but the public health authorities were not all that comfortable about outreach and publicity and the gay medical activists did not well represent the organised gay community. Little came of those recommendations. In addition, they were not incorporated into the ACIP publication. Mark Kane says, 'Efforts to control HBV infection in [gays] . . . with hepatitis B vaccine have been unsuccessful . . . [in part because of] minimal efforts to reach this group through health education and advertising' (Kane *et al.*, 'Hepatitis', 3A–12S).

29 Interview with Harold Margolis, Chief, Hepatitis Branch, CDC, January 1990. A similar statement was made to me by James Maynard, who until his retirement from the CDC was for two decades the key public health official concerned with hepatitis (interview, June 1991). This policy has just recently borne fruit. For years, the ultimate, though unexpressed, goal of the Branch was universal childhood immunisation. If all children could be routinely vaccinated, then when they experimented with sex or drugs as late adolescents and adults they would be protected without the difficulties inherent in searching out individuals engaged in private (and secret) activities. This in-house goal existed for key people probably as early as 1982 when the vaccine was licensed, certainly by the mid-1980s. By the end of the decade the data was strong enough to start publicly calling for universal vaccination. Universal vaccination for hepatitis B is now on the agenda at the CDC and is being aggressively championed on the federal level. It is hoped that the programme will be in place by 1995. (However, childhood vaccination will have little effect in actively curbing the epidemic until those children reach their early adulthood, fifteen to twenty years later.)

30 Interview with Harold Margolis, January 1990.

31 Draft, Gary Schatz, Harold Margolis and James Popham, 'Hepatitis B vaccination in the U.S.: an assessment of physicians' attitude, knowledge and behaviors' (files of Hepatitis Branch, CDC).

32 The worsening hepatitis B epidemic in the United States was fed by a number of social and cultural changes that occurred in the period 1950–90: (1) the sexual revolution, both among homosexuals and heterosexuals, which linked large numbers of people in multi-partner sex chains without the protection of barrier contraceptives such as condoms; (2) the increasing use of intravenous drugs; (3) large-scale immigration from high and moderate areas of hepatitis endemicity (Asia, Central and South America, the Caribbean); (4) the increased use of transfusions and blood exposure as the result of advances in medical technology and techniques.

33 The weaknesses of the Branch's approach to hepatitis control discussed here should not obscure their generally untiring efforts in combating the epidemic for the last two decades. That work will be discussed in greater, and more admiring, detail in a future article.

34 This view was common throughout the CDC. In 1990 when William Roper became the head of the CDC, the *New York Times* highlighted the problem, and a new desire to deal with it: 'Dr. Roper is taking over the helm at C.D.C. at a time when he and

many others believe the field of public health itself is ailing . . . One reason for the decline, . . . [a] study [by the Institute of Medicine of the National Academy of Sciences] said, is that the public health field has had difficulty adjusting to the dynamics of American politics . . . The report said it had found "much evidence of isolation and little evidence of constituency building, citizen participation" or communications with elected officials or the public by public health workers.' Dr Roper agreed with that assessment, though with the reservation that he did not want to place politics ahead of scientific fact (*New York Times*, 27 February 1990, C3).

35 Interview with Bill Borwegen, Director, Occupational Health and Safety Department, Service Employees International Union (SEIU), AFL–CIO.

36 Baruch Blumberg, 'Hepatitis B virus and the carrier problem', *Social Research*, 55, 3 (1988), 401–12, at 405.

37 Blumberg, 'Bioethical', 27.

38 14 May 1982, draft of the ACIP recommendations, 16: 'about 12,000 new carriers are added each year' as a result of new HBV infections. Others are added by migration into the US especially from South-East Asia (up to 20,000 to 25,000 per year).

39 Interview with Stephan Hadler, CDC, January 1990.

40 See Ronald Hershow, Stephen C. Hadler and Mark A. Kane, 'Adoption of children from countries with endemic hepatitis', *Pediatric Infectious Disease Journal*, 6 (1987), 431–7, at 433–4.

41 In recent years under the guidance of Harold Margolis, the Hepatitis Branch has made major headway in building a medical community constituency for universal childhood vaccination. He has been significantly helped by the creation of the National Foundation for Infectious Diseases (NFID) which has adopted hepatitis B as its special interest. The unrelenting and sophisticated 'lobbying' of the NFID was a significant factor in leading Congress to 'demand' that the CDC come up with a more effective strategy for combating the hepatitis B epidemic. The CDC hierarchy has come to endorse universal vaccination, and the ACIP has put out preliminary 'hints' to the same effect. However, these achievements may be more apparent than real. The combination of budget deficits, economic crisis and lack of extensive public knowledge and discussion of the epidemic makes the chances of actually implementing universal vaccination in the near future far from certain. There is also a real question whether the momentum for change at the CDC, in key medical professional organisations and in some congressional committees may not outstrip support in the country at large, even among state and local public health officials. Mark Kane, head of the World Health Organisation's hepatitis programme (on loan from the CDC) has clearly stated this danger (interview, July 1990). In interviews with public health officials in California and New Mexico (June and July 1990) I have found reason to believe this to be the case.

42 In one instance, in the late 1970s, there was a semi-public fight over hepatitis B carriers which eventually had a positive impact on the AIDS epidemic. It involved two court hearings concerning the integration of retarded HB carriers into the New York Public School system. The rulings ultimately offered some civil protection to people infected with AIDS. The use of those rulings for HIV people was more appropriate, unfortunately, than their applicability to hepatitis B carriers, for which

they were originally made. The decisions were legally reasonable given the presentations offered the Court, but they equalled poor public health policy for hepatitis. It is interesting that the decisions made about one disease, incorrectly I believe, were nevertheless more justifiable when applied to a later one.

II

AIDS as history

7

AIDS and British drug policy: continuity or change?

VIRGINIA BERRIDGE

There appear to have been some radical changes in British drug policy since the advent of AIDS. Since the discovery of the HIV virus among British drug users at the end of 1985, the pace of policy change has been rapid. Two major reports on AIDS and Drug Misuse have followed, together with £17 million for the development of drug services. At least a hundred needle exchanges offering new for used syringes are the most tangible public expression of new developments, underlining the view that the danger of the spread of AIDS from drug users into the general population is a greater threat to the nation's health than the dangers of drug misuse itself. British drug policy and in particular the visible manifestation of a harm-minimisation approach in the form of needle exchanges, has attracted world-wide attention. Some commentators have as a result argued that AIDS has changed the direction of British drug policy. 'The only instance of AIDS overriding established policy objectives has been in the field of drugs . . . The Government had abandoned its previous stance of augmenting its restrictive and punitive policies on drugs now that AIDS had come to be seen as the greater danger.'[1] Others have been more cautious. Gerry Stimson comments: 'these new ideas appear as a distinct break with earlier ones, but as with many conceptual and practical changes, the possibilities are inherent in earlier ideas and work. It is perhaps a matter of emphasis and direction, rather than abrupt rupture with the recent past.'[2] Susanne MacGregor is also more sceptical: 'Are we now entering a new fourth phase in British policy and practice regarding drugs, or are we seeing merely a modification to the third phase?'[3]

This paper aims to look at the question of the 'newness' of British drug policy post-AIDS. How far has drug policy been changed under the impact of AIDS? How far has AIDS been simply a vehicle whereby developments inherent in existing policy have been achieved more quickly than might otherwise have been possible? From a longer term perspective, how much is really new at all; how far do recent changes merely exemplify some very long-standing themes and tensions in British drug policy? One historical analogy is with the debates around the impact of war on social policy. Historians have in recent years begun to look more closely at the impact of the First and Second World Wars on social and health policy in particular. They have questioned the view that war was the only catalyst for radical change. In the Second World War, for example, the 'national consensus for social change' appears to have been less than unanimous; and the particular alliance of labour activism and senior civil servants of significance.[4] The roots of the National Health Service, established in 1948, can also be found not just in war-time change, but in pre-war debates and blueprints for health care. What war did was to enable this to happen more quickly and in rather a different fashion (the nationalisation of the hospitals, for example, rather than local authority control) than might otherwise have been the case. War served, too, to lay bare the deficiencies of the existing system. The chaotic overlap of hospital services and structures pre-war was quickly rationalised in the Emergency Medical Service in the war; war served to overcome vested interests and opposition to change, but essential continuities with the pre-war service remained.[5] AIDS, too, fits into this paradigm. Like war, it evoked a period of political emergency reaction which was at its peak from 1986 to 1987, but which, in the case of drugs, spilled over into 1988 with the government reaction to the Advisory Council on the Misuse of Drugs Part I Report on *AIDS and Drug Misuse*. Many of the actions of central government in this period had a war-time flavour – the creation of an interdepartmental Cabinet committee chaired by William Whitelaw, Deputy Prime Minister, the 'AIDS week' on television in February 1987, when both television companies joined together on a war-time model; the Commons emergency debate in November 1986.[6]

Drug policy in the 1980s: before AIDS

But how far did this emergency reaction stimulate genuine new departures? To analyse this question in relation to drug policy, it is first necessary briefly to sketch in developments in the preceding years. Drug policy in Britain has been characterised historically in terms of four distinct phases. The first, in the nineteenth century, saw gradually increasing professional controls inserted into a system of open availability of opiate drugs.[7] A more stringent reaction established during the cocaine 'epidemic' of the First World War heralded a new phase of policy.[8] The 1920 Dangerous Drugs Act marked a penal reaction to drug use; but the Rolleston Report of 1926 reasserted what became known as the 'British System' of medical prescribing of opiates, a system of medical control operating within a more penal framework of national and international controls.[9] It was not until the late 1960s that a new and third phase began. The development of a drugs subculture, over-prescribing by a number of London doctors, were among the factors leading to a change in policy. The second Brain Committee Report in 1965 led to changes in drug policy, in particular the limitation of the prescribing of heroin and cocaine to doctors licensed to do so by the Home Office; treatment of addiction was re-located in the 'clinics', hospital-based drug dependency units. These initially operated as prescribing centres, in the belief that 'competitive prescribing' would undercut and curtail the development of a black market in drugs. Changes in clinic policies in the 1970s, however, brought a decline in opiate prescribing and a rise in more active treatment methods, based on short-term methadone prescribing or on no prescribing at all.[10]

The 'new drug problem'

In the early 1980s, drug policy again entered a new phase. What were the main changes which characterised it? First, a 'new' drug problem began to emerge. At the beginning of the 1980s, the numbers of addicts notified to the Home Office underwent a sharp increase although the numbers had in fact been rising more slowly since the mid-1970s. The 3,425 addicts notified in 1975 had risen to over 12,000 by 1984. At the same time the amount of heroin seized by customs rocketed – from under 50 kg in 1980 to over 350 kg in 1984. The real price of heroin in London is estimated to have fallen by 20% between 1980 and 1983. The number of people involved in drug-related offences also rose steeply – from under 500 in 1975 to 2,500 in 1984. Beneath this worrying surface rise in drug-related indicators there was also a realisation that the numbers of addicts or drug users was in reality far higher than the number notified to the Home Office – a multiplier of between five and ten was suggested. Customs and police between them probably at best seized only a tenth of the drugs coming into the country; a significant black market in drugs had developed. After some years of calm, Britain was clearly in the throes of a 'new drug problem'.[11] That problem was dealt with, as this section of the paper will indicate, by changes in policy which nevertheless continued the twin track focus established in the 1920s. British drug policy remained, for all its surface change, a system of medical control operating within a framework of penal national and international policy.

Drugs and political consensus

This coincided with the emergence of drugs as a concern for politicians. Crucially, however, they became not a political issue, but one of political consensus. From about 1984, the Conservative government took a direct interest in the formation of drug policy. In 1984 an interdepartmental working group of ministers and officials, the Ministerial Group on the Misuse of Drugs, was established, for the first time bringing together the thirteen departments, from the Home Office and Department of Health to the Welsh Office and Overseas Development Administration, with an interest in the subject.[12] The Group was chaired by a Home Office Minister. This chairmanship was undertaken initially by David Mellor, who, during his tenureship of the office, adopted a high political profile as the public exponent of the 'war on drugs'. This reawakened political interest in drugs was reflected in the Commons Select Committee System also with reports from the Social Services Committee (1984–5) and the Home Affairs Committee.[13] The latter, reporting in 1986, commented that 'drug misuse, especially of hard drugs like heroin and cocaine, is still one of the UK's most distressing and difficult problems. Drug dealers still make princely profits and threaten us all, including our children, with a nightmare of drug addiction which has now become a reality for America.'[14] There were some signs that drugs might even emerge as an issue for political division between the parties. In 1985, David Owen, leader of the Social Democratic Party, gave a lecture in which he cited research evidence linking drug use with youth unemployment, and deprivation.[15] But the incipient debate did not develop. In the 1987 general election the SDP/Liberal Alliance manifesto did not mention drugs and an election leaflet on health policy gave it no more than a mention. Labour's manifesto was likewise silent. Any argument was, as one commentator noted, 'about how *much* rather than *what* should be done'.[16] Some commentators have seen the 1980s as characterised by the politicisation of drug policy.[17] But drugs in fact never became a party political issue, an issue for division between the parties. Drug control became an issue particularly associated with the Conservative government. But policy was essentially consensual and the main opposition parties did not significantly differ in their approach. In this drug policy was a model for later AIDS policy making, where issues of political difference between the parties were equally blurred.

The 'war on drugs'

The public face of Conservative political interest was a policy focused on a strong penal response to drugs, on both domestic and international fronts. In 1985, the government published the first version of its strategy document for drugs, *Tackling Drug Misuse*.[18] The strategy had five main aspects, three of which were penal in orientation. Its aims were:

1. Reducing supplies from abroad
2. Making enforcement even more effective
3. Maintaining effective deterrents and tight domestic controls
4. Developing prevention
5. Improving treatment and rehabilitation

In the same year, the Commons Home Affairs Committee, in its interim report, called for continued enforcement of the law; the stationing overseas of additional customs and police intelligence liaison officers; harsher penalties for trafficking offences; help for crop eradication and substitution schemes; legislation to attack and seize the profits of traffickers; and changes in banking law to impede the disposal of money derived from drug trafficking.[19] Much of this was put into effect. The Drug Trafficking Offences Act 1986 (in force since 1987) provided (with all-party support) comprehensive powers for tracing, freezing and confiscating drug money, along with measures to stop the laundering of drug money. The Controlled Drugs (Penalties) Act 1985 increased the maximum penalty for drug trafficking from fourteen years to life. Drug policy assumed new visibility at the level of international control. Increasingly, too, it acquired a European dimension. Britain had chaired the Pompidou Group (the Council of Europe Co-operation Group to Combat Drug Abuse and Illicit Trafficking in Drugs) since 1984. The arrival of a single European market in 1992 brought questions of drug control to the fore. Clearly a penal reaction largely out of favour since the 1920s was back in fashion. What it meant in actual practice was rather more uncertain; but certainly the penal response remained a powerful political, if rhetorical, symbol.

Health policy on drugs: a time of change

One aspect of policy which it did symbolise was the decline of a primarily medical response to drugs. British drug policy, as established in the 1920s, had a twin-track approach of penal control, symbolised by the lead role in policy taken by the Home Office, but also of a medical reaction, underpinned by the departmental interest of the Ministry of Health. Since the 1926 Rolleston Report British drug policy had been based on a medical response to drug addiction, symbolised in that report by its reaffirmation of the disease model of addiction and by a doctor's clinical freedom to provide maintenance doses of opiate drugs as a form of treatment. The Rolleston Committee, although arising out of Home Office concern, was established as a Health Ministry Committee, and serviced by the Ministry, in particular by its doctor–civil servant Secretary, E. W. Adams. But the resultant 'British system' of medical control operated as part of a legal system based on penal sanctions and international controls as laid down in the 1912 Hague Convention and the 1919 Versailles settlement.[20] How the balance operated could vary over time.

In the 1980s, that balance did begin to shift towards a penal response. But the 'British System' had in fact been in decline well before the Conservative government introduced its package of penal measures in 1984–6. The shift in the health side of drug policy had begun in the mid-1970s. It was marked by a number of factors; a decline in medical prescribing of opiate drugs and of the clinics as centres for the treatment of drug addiction; a change in the characterisation of drug addiction; the rise of the voluntary sector and of drug treatment as part of primary health care. Perhaps most important of all, it had seen the consolidation of a new 'policy community' round drugs and the emergence (or re-emergence) of the concept of harm-minimisation as an objective of policy. It is worth looking briefly at all of these developments. The specialist model for the treatment of drug addiction within the National Health Service as exemplified by the clinic system did not long adhere to the original blueprint. Between 1971 and 1978, the amount of heroin prescribed fell by 40%.[21] Increasingly, injectable and oral methadone were used as substitutes for heroin, following the American example; short-term treatment contracts based on withdrawal replaced longer term prescribing. The clinics were effectively treating only addicts who were highly motivated to come off drugs. The reasons behind this change in treatment policy were complex and focused on clinic doctors' need to provide 'real treatment', rather than simply acting as glorified shopkeepers by handing out injectable heroin. The conflicts between the professional perceptions and needs of doctors working in the clinic system and the 'non-medical' paradigm of junkies who simply wanted an available source of heroin, recur in the medical literature of the time. This change in clinic policy was legitimated by research. A controlled trial of oral methadone prescribing versus injectable heroin conducted by researchers at University College Drug Dependence Unit (DDU) provided the rationale for seeing the change of approach as a scientific issue rather than as one driven by professional needs.[22] These developments, together with cuts in funding and resources, ensured that the clinics, by the early 1980s, had become what Mike Ashton called 'a backwater of our social response to drug abuse'.[23] Withdrawal from prescribing was a central feature of the medical response. This change of tactic was enshrined in the *Guidelines of Good Clinical Practice* distributed to all doctors in 1984, which emphasised the limited role prescribing had to play.[24] The weight of professional opinion against prescribing was demonstrated by the case of Dr Ann Dally, brought before the General Medical Council in 1987 for technical offences involved in prescribing in her private practice.

The 'medical model' of addiction as a disease requiring specialist treatment was disappearing in practice – and in theory as well. The older concept of addiction had given place, in official language at least, in the late 1960s, to the concept of dependence, enshrined in an official World Health Organisation definition.[25] But in the 1980s, this changed to the concept of the problem drug taker, paralleling similar developments in the alcohol field. The change in definitions received official sanction in the 1982 Advisory Council on the Misuse of Drugs Report on *Treatment and Rehabilitation*, which declared

> most authorities from a range of disciplines would agree that not all individuals with drug problems suffer from a disease of drug dependence. While many drug misusers do incur medical problems through their use of drugs some do not. The majority are relatively stable individuals who have more in common with the

> general population than with any essentially pathological sub-group . . . There is no evidence of any uniform personality characteristic or type of person who becomes either an addict or an individual with drug problems.[26]

The 'normality' of the drug taker, an essential component of the sociology of deviance since the 1960s along with the sociological critique of disease and deviance, thereby received legitimation at an official policy level.

Accompanying this change in definitions was an emphasis on a multidisciplinary approach, based on regional and district drug problem teams and local drug advisory committees. Although medical personnel would continue to take the lead, the involvement of other agencies, local authorities, police and voluntary agencies was actively sought. The voluntary agencies in particular had already been playing a more prominent role in the provision of services since the late 1970s. The *Treatment and Rehabilitation* Report encouraged a partnership between them and the statutory services. In 1983, the Department of Health mounted a Central Funding Initiative for the development of drug services on a national basis. Between 1983 and 1987, £17.5 million was made available for the development of new community-based services. The majority of grants, 56%, were administered through health authorities; 42% through the voluntary sector.[27] The aim was to displace the old hospital-based London-focused specialist treatment system. A senior Department of Health civil servant recalled,

> Brain had bunged clinics into London . . . The most important thing was to try and get a few more services up and running . . . We had to get the voluntary and hospital services working together. We had to say to generalists and generic workers that the problems of drug users are the same as others – get on and deal with this homeless person and forget he's a drug user.[28]

This approach met resistance from a variety of quarters, from some of the London clinic establishment and from some voluntary agencies, suspicious of incorporation.

But the first half of the 1980s was marked also by the formation of a new 'policy community' around drugs. Richardson and Jordan have used this concept to delineate the way in which the central policy-making machinery is divided into sub-systems in departments (organised round areas such as alcohol or drugs).[29] Close relationships can develop between these sub-systems and outside pressure groups, involving shared policy objectives and priorities. For drugs, the 1980s saw a shift from a primarily medical policy community to one which was more broadly based, involving revisionist doctors, the voluntary agencies, researchers and, most crucially, like-minded civil servants within the Department of Health. The change can be characterised through the changed membership of the Advisory Council on the Misuse of Drugs (ACMD), the main expert advisory body on drug policy. In the 1980s, it recruited to an originally mainly medical membership representatives of the voluntary agencies, health education, social science research, the probation service and general practice.[30] The increase in drug use in Liverpool and Wirral attracted much attention; non-medical researchers and service workers there were of key importance in advocating the thesis of the 'normalisation' of drug use. But doctors also played a key role there; and it was in the Manchester area that revisionism received its clearest expression. The Regional Drug Dependence consultant introduced a 'new model service' based on satellite clinics, community drug teams and a regional drug training unit.[31] Developments such as these were actively encouraged by civil servants in the Department of Health. The aim was to encourage a more bottom-up approach, to try and bring the voluntary agencies, drug and ex-drug users into a more active relationship with services.

This new policy community took the conclusions of the *Treatment and Rehabilitation* Report as its bible. There were differences over questions of implementation and practice. The 1982 report's recommendations were, for example, criticised for establishing the regional drug problem team as basically the staff of a specialist service, headed by a consultant psychiatrist, rather than a genuine multi-disciplinary and agency partnership; and there were also differences over questions of prescribing. But another policy objective, that of the minimisation of harm from drug use, found general support. This was an aim which had long received support from within the voluntary sector of drug services and also from doctors critical of the clinics' non-prescribing policies and their consequent effect on the black market. But it also became an official policy objective in the 1980s. In 1984, the ACMD's Report on *Prevention* abandoned earlier divisions into primary, secondary and tertiary prevention in favour of two basic criteria: (a) reducing the risk of an individual engaging in drug misuse; (b) reducing the harm associated with drug misuse.[32] But such objectives remained difficult to enunciate publicly in relation to drug use. When, in 1981, the Institute for the Study of Drug Dependence published a pamphlet, *Teaching about a Volatile Situation*, advocating harm-minimisation techniques (safe sniffing) for glue sniffing, there was an outcry which nearly brought an end to the Institute.[33] There was still a yawning gap between the 'political' and 'policy community' view of drugs. This gap was epitomised in the furore surrounding the government's decision to mount a mass media anti-heroin campaign in 1985–6. This essentially political decision ran counter to received research and internal policy advice which concluded that such campaigns should not be attempted and were potentially counter-productive.[34] Here again, drug policy provided a model for later developments over AIDS. The model of a mass media campaign proved uncontroversial once the anti-heroin campaign had preceded it.

To sum up, 1980s drug policy pre-AIDS had a dual face – a 'political' penal policy with a high public and mass media profile; and an 'in-house' health policy based on a rhetoric of de-medicalisation and the development of community services and harm-minimisation. There were undoubtedly similarities and continuities between both wings of policy – the focus on community mobilisation, for example (although the parents' groups on Merseyside differed from the 'junkie union' model of drug user participation). The relationship between the rhetoric of policy and the nature of practice in both wings was also paradoxical. Changes in the health aspects of policy were still largely dependent on the power of medical expertise in policy formation. Medicine might, as Jerry Jaffe commented in his 1986 Okey lecture, no longer sit at the top of the table, but the new system could not have moved forward if doctors and doctor civil servants had not wanted it.[35]

The impact of AIDS: the crisis response

What was the impact of AIDS upon an area of policy already in a state of flux? The nature of the problem presented by drug use changed. Late in 1985 reports from Edinburgh revealed a prevalence of HIV antibody seropositivity among injecting drug misusers which was considerably higher than in the rest of the United Kingdom and also higher than in parts of Europe and the United States.[36] The issue of potential heterosexual spread was not new. The blood transfusion question and the spread of the virus among haemophiliacs had in 1983/4 raised the question of the spread of the virus into the general population.[37] This was already part of the emergent AIDS 'policy community's' position. But drugs made the issue of spread into the general population more urgent. A Scottish Committee chaired by Dr D. McClelland, Director of the South-East Scotland Regional Blood Transfusion Service, was set up to review the Scottish situation and to report on how to contain the spread of HIV infection and allay public concern. The report of this committee, published in September 1986, foreshadowed many of the more publicised statements of the later ACMD Reports.[38] It enunciated harm-minimisation as a primary objective. The threat of the spread of HIV into the general population justified a response based on the minimisation of harm from drug use and on attracting drug users into contact with services.

> There is . . . a serious risk that infected drug misusers will spread HIV beyond the presently recognised high risk groups and into the sexually active general population. Very extensive spread by heterosexual contacts has already occurred in a number of African countries . . . There is . . . an urgent need to contain the spread of HIV infection among drug misusers not only to limit the harm caused to drug misusers themselves but also to protect the health of the general public. The gravity of the problem is such that on balance the containment of the spread of the virus is a higher priority in management than the prevention of drug misuse.

Substitute prescribing and the provision of sterile injecting equipment to addicts were two major means by which these ends were to be achieved.

Members of the new policy community began to voice these objectives more openly. David Turner, co-ordinator of SCODA, the Standing Conference On Drug Abuse, the national co-ordinating body for the voluntary drug sector, commented at an AIDS conference in Newcastle in 1986, 'it is essential that no risk-reduction option is rejected out of hand because it appears to conflict with a service's stated goal of abstinence'.[39] Reports of Dutch harm-reduction strategies and needle exchange projects became more frequent.[40] Social science researchers joined in. These objectives were, as before AIDS, shared by civil servants in the Department of Health. 'We're going to get harm minimisation much more quickly' commented one senior non-medical civil servant (to the author) in the autumn of 1986.[41] Another saw it as the opportunity

> to go out and push out a bit further. Almost fortuitously the fact we'd already shifted our policy . . . was . . . a fertile seed bed from which we've been able to develop . . . We'd be weeping in our tea now . . . The pre-existing development of community services enabled us to get harm-minimisation approaches off the ground more rapidly than if we'd been rooted in the old hospital based approach to drug misuse.[42]

The urgency of the situation enabled what had been a stumbling block to the unspoken objectives of drug policy pre-AIDS – political and media opposition to any suspicion of 'softness' on drugs – to be quietly overcome. Research was an important legitimating factor. In December 1986, Norman Fowler, Secretary of State for Social Services, announced the intention to set up a number of pilot needle exchange schemes (building on some already in operation, in Liverpool and Swindon, for example). Assessment of effectiveness in preventing the spread of the virus was an important consideration. There were doubts in the Cabinet Committee on AIDS (set up in October 1986) about the provision of syringes; and early in 1987 a project to monitor and evaluate the pilot schemes was established at Goldsmith's College. In May 1987, the ACMD set up its own working group on AIDS and drug misuse, chaired by Ruth Runciman, a non-medical member of the Council. Of the working group's thirteen members, six were non-medical. Part of the ACMD's Report, ready in the autumn of 1987, was not published by the government until March 1988, causing disquiet among some members of the working party.[43] The report, like the McClelland committee before it, declared the danger of the heterosexual spread of the virus to be a greater menace than the danger of drug use itself. It called for a range of harm-minimisation strategies, most notably needle exchange and over the counter sales of syringes by pharmacists. Prescribing, too, was seen as an option to attract drug users into services. But the initial political reaction was lukewarm.

Although the goal of harm-reduction was accepted by Tony Newton, Minister of Health, in his statement to the Commons on 29 March 1988, only £1 million was provided for the development of services and the further results of evaluation were awaited. The response from Michael Forsyth, Scottish Health Minister, saw central funding of the two pilot schemes still in operation at an end – and a generally negative response to the particular criticisms of the Scottish situation in the ACMD Report. It seemed as though policy would founder on the rocks of political opposition. The summer of 1988 saw intense pressure from civil servants for a more positive response from ministers which brought a turn-around in the autumn, aided by research results from the Goldsmiths' group which showed that users did change to lower risk behaviours (although a disappointingly small proportion of attenders stayed on to achieve them).[44] David Mellor, the new Health Minister, announced an extra £3 million for the provision of services in England. The money was specifically to enable services to expand and develop in such a way as to make contact with more drug misusers in order to offer help and advice on reducing the risk of HIV infection. Only £300,000 was allocated to Scottish services, despite the disparity in numbers of HIV positive drug users there by comparison with England. Further money followed for 1989/90 with an extra £5 million available for the development of drug services. Coming on top of pre-existing AIDS allocations, the extra funding since 1986 gave health authorities at least £17 million to spend on drug services; money was being provided, too, on a recurrent basis. In Scotland the 1989/90 figure of £2.1 million for drug services was less significant than the doubling of the general AIDS allocation to £12 million. For some English projects funded by the Central Funding Initiative (CFI), the money came just in time.

The 'normalisation' of drug policy through AIDS

What, then, had AIDS really meant for drug policy? At the level of policy formulation it had clearly, on the war-time model, meant the public establishment of the previous largely unspoken aims of policy. Drug policy in general and services in particular had ostensibly come out of the ghetto and the process, instigated pre-AIDS, of integration into the normal range of services had been intensified. The message of government advertising on drugs changed, initially away from the mass shock approach to targeted harm-minimisation. A senior medical officer commented, 'AIDS may be the trigger that brings care for drug users into the mainstream for the first time ever . . . The drug world can come "in from the cold" through AIDS . . . it's a golden opportunity to get it right for the first time.'[45] Drugs, so it was argued, became a problem of public health rather than a question of individual pathology. Gerry Stimson argued,

> HIV has simplified the debate and we now see the emergence of what I will call the public health paradigm. Rather than seeing drug use as a metaphorical disease, there is now a real medical problem associated with injecting drugs. All can agree that this is a major public health problem for people who inject drugs, their sexual partners, and their children.[46]

AIDS, so it seems, went some way to achieving the normalisation of drug use. In declaring prescribing to be a legitimate option, it appeared to deal with the prescribing question which had bedeviled drug policy in the 1970s and 80s. The new 1980s policy community around drugs was strengthened by the support of some key politicians. References to normalisation and attracting drug users to services began to appear in Hansard as well as the pages of the in-house drug journals.[47] The media were diverted away from heroin into the cocaine issue. For some members of the policy community AIDS opened up the wider agenda of the liberalisation of drug policy.[48] British policy had historically differed from the American approach to drug control although some commentators had argued that the two systems were drawing closer in the 1970s. But AIDS served to underline some radical differences in approach; harm-minimisation was not adopted as official policy in the United States. Why that was so is a complex story which cannot be fully addressed here and to which Warwick Anderson refers in the succeeding chapter. Among the salient factors were a less significant and shorter history of medical involvement in policy making in the US; the decentralisation of aspects of health policy by comparison with the Federal and political nature of the 'war on drugs'; and the ethnic dimension to the harm-minimisation issue in the US (official black leaders condemned the approach as 'genocide') which was completely absent in the UK.

A new departure for drug policy?

Policy in the UK is clearly in a state of flux and any historian would be unwise to attempt to lay down definitive statements about either present or future directions. The rest of this paper will simply raise a number of questions about the 'new drug policy' in the light of an historical perspective. It will argue that in general the changes, although real enough, exemplify and expand on long-standing themes and tensions within British drug policy. It will look specifically at five areas; at questions of the implementation of policy and whether this represents demedicalisation or remedicalisation; at the 'newness' of the 'new public health approach' to drugs; at the issue of syringe exchange in the light of the past history of technological change and of scientific research on drug policy; at tensions between penal and medical approaches; and finally, at the long-term history of harm-minimisation as a policy objective.

The implementation of policy: demedicalisation or remedicalisation?

The nature of the implementation of policy is important, for the rhetoric of policy and its practice can differ significantly.[49] Undoubtedly, local 'policy traditions' have been important, as, for example, in Scotland, where psychiatrists traditionally had little to do with drug users and where infectious disease specialists and GPs initially took on the increased medical involvement in drug use which resulted from the spread of HIV. AIDS while nominally 'normalising' drug use, in some respects appears to have brought a revival of medical involvement both in practical terms and in conceptualisation of the issue. Doctors have become more central through the emphasis on prescribing as an option and the focus on the role of the general practitioner. There is also a new emphasis on the general health of drug users. Clinic doctors have begun to become interested in issues such as hepatitis B and the general health of drug users, whereas previously these had hardly figured as part of clinic work. A consultant commented,

> What's disturbing is that I have had to change positions. I hadn't seen doctors as being that important in services . . . There were nineteen CDTs in X, each one autonomous and funded by the NHS, but only one headed by a doctor and the others would be headed by a community nurse, a social worker, a voluntary worker . . . Now I've started arguing strongly that all drug services need a lot of doctor input . . . The impact of AIDS means an urgent need for medical care . . . Drug services will have to do routine health checks and be proactive in selling it.[50]

Such views were echoed at an official level. The need, underlined by the McClelland and the two ACMD Reports of contacting drug users not normally in contact with services served to elevate the notion of treatment which resumed its place as an unchallengeable good. Part of the critique of drug policy in the 1970s aimed to move away from drug abuse/addiction as a medical condition requiring treatment. But AIDS served to bring treatment back to the centre of attention and the earlier arguments fell from favour. In another respect, too, AIDS served to revive earlier 'medical' arguments and themes in drug policy. The arguments for prescribing methadone as a 'bait' to attract people into services and hence away from syringe sharing practices reproduced arguments in favour of the medical approach originally advanced in the 1960s and 70s. Then, too, prescribing was an option which, so it was considered, would attract addicts to services and undercut the black market. The 'competitive prescribing' argument, criticised at the time, revived via AIDS.

The role of the voluntary sector in drug services and its relationship to medical practice has also been affected. Ben Pimlott's comment that the Thatcher government, with its rhetoric of voluntarism, had seen the virtual abolition of the voluntary sector may have been exaggeration, but it did contain an element of truth.[51] The voluntary sector, in drug services as in AIDS more generally, was drawing closer to the statutory sector, and was often funded by it. The 'contract culture' brought about by National Health Service (NHS) funding changes made this tendency clearer. Even within the voluntary sector, drug use, because of HIV, had become associated with illness. 'They champion the drug users' rights to treatment and to use drugs if they want because they have an illness and need a script . . . The voluntary sector ends up holding a disease model.'[52] Increasingly, voluntary (non-medical) and statutory (medical) services were being brought into a closer relationship and the differences between them blurred. This was a process which pre-dated AIDS and owed much to more general trends in health policy.

Whether this can be seen as demedicalisation or remedicalisation largely depends on individual perspective. But so far as the power relationships in policy making went the situation exemplified the long-standing policy influence of the medical profession. Without the support of influential and centrally placed doctors, the 'new departures' in policy could not have been sustained. Drug policy making after, as before, AIDS has exemplified the influence of doctor civil servants as important in policy making, a tradition going back to Dr E. W. Adams, a Ministry of Health civil servant and Secretary of the Rolleston Committee in 1924–6.[53] The role of Dr Dorothy Black, senior medical civil servant in the Department of Health was an important one. Social science expertise was brought into a policy advisory role; but medical expertise in defining policy as for example through the role of the medical expert adviser to the Department of Health remained central. To sum up, then, the 'non-medical' rhetoric of policy post-AIDS disguised some clear tendencies towards sustained or even increased medical input in terms of treatment and services and revived some old medical-focused arguments of the 1960s. The nature of the symbiosis between medical and non-medical at the practical level is unclear and varied locally. Quite who was incorporating whom depends on perspective. At a national policy level, however, the centrality of medical influence remained.

The 'new public health' approach?

One aspect of this symbiotic inter-relationship between medical and non-medical has been the incorporation of drug use into a public health model of response. Two issues are central here. First that a 'public health' response to drug use is nothing new. Historically such responses have often been triggered in times of perceived crisis. Secondly, definitions of public health are themselves historically specific; the image of nineteenth-century environmentalist public health which this language conveys is far from the individual focused public health of the 1980s and 90s. To take crisis and the public health response first – one observer commented in 1988 on the parallels between the Advisory Council's Part I Report on *AIDS and Drug Misuse* and the second Brain Committee's Report on drug addiction in 1965.[54] Like the ACMD, Brain also justified change in drug policy on public health grounds – addiction was a 'socially infectious condition', a disease which 'if allowed to spread unchecked, will become a menace to the community'. The remedies suggested by Brain – including notification and compulsory treatment – were classic public health responses. The balance required in drug policy in the 1980s between minimising the harm from drug use but not thereby promoting drug use is paralleled by Brain's attempt to graft the public health objective of preventing infection on to a system geared to individual treatment; drug workers had to prescribe opiates to undercut the black market, but not so much that the market was supplied and new addicts created. There have always been tensions in drug policy, not simply between penal and medical forms of control, but between different forms of medical input either focused on the community or on the individual. In the nineteenth century, a 'public health' focus on opium adulteration, on child doping or working-class industrial opiate use was stimulated by the urban crisis of industrialisation. This gave place to individually focused medical theories of addiction and disease.[55] Roy MacLeod has pointed to the focus on individual pathology rather than an environmentalist approach in late nineteenth-century discussions of inebriety.[56] Likewise, Brain's public health focus in 1965 was modified in practice to a focus on active medical treatment. There has always been an implicit tension between preventive and curative approaches, in this as in other areas of health policy.

The 'public health' paradigm itself, too, is worth closer examination – for 'public health' has not been an unchanging absolute. Its definition and remit has changed in the twentieth century, as the nature of state intervention in social issues has itself shifted.[57] The environmentalist public health of the mid-nineteenth century narrowed under the impact of the bacteriological revolution. Social hygiene with its emphasis on individual responsibility for health was the reformulated public health of the 1900s; the 1970s and 1980s public health has, in its emphasis on individual lifestyle and on prevention, revived these earlier social hygienist concerns. Drug policy, both pre- and post-AIDS, with its emphasis on health education, on the role of the voluntary sector, on the drug user as a 'normal' individual responsible for his or her own actions and health, has epitomised some key elements of the redefinition. Certainly the 'public health paradigm' of post-AIDS policy is nothing new.[58] As with past 'public health' responses the potential for a shift to an individualistic medical response is present. The conceptual distance is, on current definitions, not a large one.

Syringe exchange: the history of technological change, research and policy

Changes in British drug policy have been particularly associated with the role of syringe exchange. The acceptance of this institutional practice has been seen by many commentators as epitomising the radical change in British drug policy brought by AIDS. There is no doubt that British policy is, in this respect, significantly different from that of some other countries, most notably the United States. But the conceptualisation of syringe exchange as a radical new non-medical departure in policy is not wholly convincing, given the past history of policy change. Two issues come into focus here: the relationship between changing medical technology and the impetus for policy change; and the legitimation of controversial policy change through its redefinition as a technical medical and scientific issue. Both of these issues have a history in the drug policy arena; and both are illustrated in the case of the adoption and policy use of syringe exchange. Carol Smart, in her analysis of twentieth-century British drug policy, noted the connection between developments in scientific knowledge and consequent new technologies capable of regulating and processing addicts and the impetus for policy change. Methadone, urine screening and rational systems of collecting information via notification were, in her argument, particular examples of technological regulation of relevance to the policy changes of the 1960s.[59] Moving back into the nineteenth century, the introduction of another technical medical procedure – the hypodermic syringe – also helped dramatically to shift the response to drug use in the 1870s and 80s.[60] The change of focus from a public health to an individualist medical response to drug use via disease theories of addiction was linked to perceptions of the dangers brought by this form of technological change. In the 1980s, too, policy change was again symbolised in syringe exchange by a technical medical procedure. Yet the association between harm-minimisation approaches and the hypodermic syringe was not automatic. Some of the pre-AIDS discussion of this overall objective had envisaged the evaluation of a range of different non-technical, non-medical 'safe use' procedures. Smoking heroin was among them. The danger of encouraging injecting use where the local culture was not an injecting one was also discussed.[61] But policy change post-AIDS was closely entwined with the syringe exchange approach, a focus which had its antecedents in the 1880s and 1960s.

The association of policy change with syringe exchange was also legitimated at a political level by its redefinition as a technical issue. Responsibility for controversial decision making was deflected on to the 'objective' process of research. The epidemiologically focused research of the Monitoring Research Group at Goldsmiths' College was of central importance in winning political acceptability for a potentially controversial policy change. The involvement in the research of a leading social scientist, Gerry Stimson, symbolised one aspect of the alliance between medical and non-medical expertise which has been a continuing theme of recent policy. Reginald Smart, of the Canadian Addiction Research Foundation, noted, in a commentary on the Goldsmiths' group's results, that the support given in the findings for the efficacy of syringe exchange as a means of achieving the objective of harm-minimisation was hardly convincing.[62] But in policy terms, this type of comment mattered less than the legitimation the research provided for politicians nervous about a policy change urged by the drug 'policy community'. The relationship between research and policy in this instance again recalls policy change in the 60s and 70s. The Hartnoll-Mitcheson controlled trial of heroin versus methadone had legitimated policy change in the clinics via a 'scientific' procedure. As in the 1980s, some critics had then argued that the substantive data did not fully support the policy change laid upon it. Oral methadone was in fact found to lead to decreased clinic attendance and a greater degree of involvement in the black market. Again the important issue was less the detailed results of the research and more the policy change it appeared to support. In both cases the redefinition and refocusing of controversial policy change into a scientific and technical issue (epidemiology in both instances) secured the relatively painless passage of a policy objective into practice.

Tensions between penal and medical approaches in policy

It is a commonplace to analyse drug policy in terms of competing penal and medical forms of control. Here AIDS has brought change – but the continuities with historical themes are also strong. Most obviously the twin-track nature of British drug policy remains in existence post-AIDS. Penal policy still remains, albeit modified at the local level. Britain still adheres to a system of international control of drugs and there has been little modification of this at the international or European levels. In 1989, one senior Conservative politician succinctly summed up his view of drug control as 'increased controlled availability at home and stronger prohibition round the edges'.[63] How far the 'normalisation' of the drug user has penetrated beyond specialist drug and political circles is also debatable. Some of the exchanges in the House of Commons Social Services Committee hearings on AIDS in 1987 were notable by a distinctly harsher attitude on the part of politicians to drug users than to gays.[64] At the local level in Britain there have been changes in the balance between penal and medical with police co-operation in the establishment of needle exchanges, police participation in local drug advisory committees and links between police and services. The prisons issue has in particular symbolised the shifting balance between penal and medical. At one level, British prison policy has not changed to accommodate the demands for syringe and condom provision to prison populations enshrined in a 1986 World Health Organisation (WHO) document. But the balance between penal and medical is changing. The potential impact of HIV among over-crowded prison populations has been one impetus among many behind the government's *Crime, Justice and Protecting the Public White Paper* (1990) which introduces the option of the diversion of drug users into treatment rather than imprisonment.[65] An historically minded observer could point to a long tradition of compulsory treatment in the drug and alcohol area with its roots in the inebriates legislation of the late nineteenth century. As Timothy Harding has commented, HIV 'has emphasised the health aspects of the penal response'.[66] As with the medical/non-medical alliance, the balance of power within the relationship is currently unclear.

The history of harm-minimisation

This article has suggested that, despite the apparent revolution in the public rhetoric of drug policy achieved by AIDS, many aspects of post AIDS policy were already inherent in drug policy in the 1980s. Harm-minimisation is one obvious example which has already been discussed. But harm-minimisation itself also has its history before the 1980s. It is only a restatement in different circumstances of the principles enumerated in the Rolleston Report of 1926.

> When, therefore, every effort possible in the circumstances has been made, and made unsuccessfully, to bring the patient to a condition in which he is independent of the drug, it may . . . become justifiable in certain cases to order regularly the minimum dose which has been found necessary, either in order to avoid serious withdrawal symptoms, or to keep the patient in a condition in which he can lead a useful life.[67]

Harm-minimisation, although not categorised in those terms received a clear expression in the 1920s; and it has been the basis of the British approach to drug control for much of the twentieth century. If one looks back even further, into the nineteenth century, one focus of the professional self-regulation approach (apart from the establishment of professional status) was also the minimisation of harm to the customer.[68]

Conclusion: the long-term impact of policy change

The question of the long-term impact of policy change should also be considered. How long will the revived 'public health paradigm' persist? It would be an unwise historian or policy scientist who attempted to predict what the long-term balance of policy might be. The analogy of war and policy change with which this paper began does offer some suggestive indications. The 'public health' response to alcohol in the First World War with state control of the alcohol industry and limited pub opening hours only partially survived the war.[69] The 'hard-line' emergency response to drugs at the same period was moderated in the 1920s.[70] War does lead to change – but long-standing themes and tendencies also express and reassert themselves. As this paper has argued, the overall balance of power within policy is too complex and historically specific to be adequately subsumed under rhetorical barriers such as the 'public health' approach or the 'normalisation' of drug policy. Indeed, the overall impression is of some long-standing tendencies – the role of medicine, the penal approach, even the revival of the nineteenth-century role of the pharmacist – which have not been undermined and may even have been enhanced by the impact of AIDS.[71] Whatever the future of drug policy in its post-AIDS years, it will not escape from its history.

Acknowledgements

I am grateful to Philip Strong for comments on an earlier draft and to the Nuffield Provincial Hospitals Trust for financial support for the research on which this paper is based. My thanks are due to Ingrid James for secretarial assistance.

NOTES

1 D. M. Fox, P. Day and R. Klein, 'The power of professionalism: AIDS in Britain, Sweden and the United States', *Daedalus*, 118 (1989), 93-112.

2 G. Stimson, 'AIDS and HIV: the challenge for British drug services', *British Journal of Addiction*, 85 (1990), 329–39.

3 S. MacGregor, 'Choices for policy and practice', in S. MacGregor (ed.), *Drugs and British Society. Responses to a Social Problem in the 1980s* (London, 1989), 171–200.

4 C. Webster, 'Conflict and consensus: explaining the British health service', *Twentieth Century British History*, 1, 2 (1990), 115–51.

5 For discussion of these issues, see C. Webster, *The Health Services since the War*, vol. I: *Problems of Health Care. The National Health Service before 1957* (London, 1988); also Daniel M. Fox, 'The National Health Service and the Second World War: the elaboration of consensus', in H. L. Smith (ed.), *War and Social Change. British Society in the Second World War* (Manchester, 1986), 32–57.

6 V. Berridge and P. Strong, 'AIDS policies in the UK: a preliminary analysis', in E. Fee and D. Fox (eds.), *AIDS: The Making of a Chronic Disease* (Berkeley, 1992).

7 V. Berridge and G. Edwards, *Opium and the People: Opiate Use in Nineteenth Century England* (London, 1987).

8 V. Berridge, 'War conditions and narcotics control: the passing of Defence of the Realm Act 40B', *Journal of Social Policy*, 1 (1978), 285–304.

9 V. Berridge, 'Drugs and social policy: the establishment of drug control in Britain, 1900–1930', *British Journal of Addiction*, 79 (1984), 17–29.

10 MacGregor, 'Choices for policy and practice'; P. Bean, *The Social Control of Drugs* (London, 1974); G. Edwards, 'Some years on: evolutions in the "British System"', in D. H. West (ed.), *Problems of Drug Abuse in Britain* (Cambridge, 1978); H. B. Spear, 'The growth of heroin addiction in the United Kingdom', *British Journal of Addiction*, 64 (1969), 245–55.

11 G. Stimson, 'British drug policies in the 1980's: a preliminary analysis and suggestions for research', *British Journal of Addiction*, 82 (1987), 477–88.

12 Home Office, *Tackling Drug Misuse: A Summary of the Government's Strategy* (London, 1986).

13 Social Services Committee, *Fourth Report of the Social Services Committee: Misuse of Drugs with Special Reference to the Treatment and Rehabilitation of Misusers of Hard Drugs* (London, 1985).

14 Home Affairs Committee, *First Report from the Home Affairs Committee, Session 1985–86: Misuse of Hard Drugs* (London, 1986).

15 D. Owen, 'Need for a scientific strategy to curb the epidemic of drug abuse in the United Kingdom', *Lancet*, 26 (October 1985), 958.

16 'Election 87, What the parties said about drugs', *Druglink*, 2, 5 (1987), 7.

17 For example, G. Stimson, 'The war on heroin: British policy and the international trade in illicit drugs', in N. Dorn and N. South (eds.), *A Land Fit for Heroin? Drug Policies, Prevention and Practice* (London, 1978), 35–61.

18 Home Office, *Tackling Drug Misuse*.

19 Home Affairs Committee, *Interim Report. Misuse of Hard Drugs* (London, 1985).

20 V. Berridge, 'Drugs and social policy'.

21 R. Lewis, R. Hartnoll, S. Bryer, E. Daviaud and M. Mitcheson, 'Scoring smack: the illicit heroin market in London, 1980–83', *British Journal of Addiction*, 80 (1985), 281–90.

22 R. L. Hartnoll, M. C. Mitcheson, A. Battersby, G. Brown, M. Ellis, P. Fleming and N. Hedley, 'Evaluation of heroin maintenance in controlled trial', *Archives of General Psychiatry*, 37 (1980), 877.

23 M. Ashton, 'Controlling addiction: the role of the clinics', *Druglink*, 13 (1980), 1–6.

24 Department of Health and Social Security (DHSS), *Guidelines of Good Clinical Practice in the Treatment of Drug Misuse. Report of the Medical Working Group on Drug Dependence* (London, 1984).

25 G. Edwards, A. Arif and R. Hodgson, 'Nomenclature and classification of drug and alcohol related problems', *Bulletin of World Health Organisation*, 59 (1981), 225–42.

26 DHSS, *Treatment and Rehabilitation. Report of the Advisory Council on the Misuse of Drugs* (London, 1982).

27 S. MacGregor, B. Ettorre, R. Coomber and A. Crosier, *The Impact on Drug Services in England of the Central Funding Initiative* (London, 1991).

28 Dr Dorothy Black speaking at Hatfield Polytechnic conference, June 1989.

29 A. G. Jordan and J. J. Richardson, *British Politics and the Policy Process* (London, 1987).

30 The membership of the ACMD is listed at the front of DHSS, *Treatment and Rehabilitation*, and Home Office, *Prevention. Report of the Advisory Council on the Misuse of Drugs* (London, 1984). Membership of the Working Group on AIDS and Drug Misuse is listed in the two ACMD AIDS reports, *AIDS and Drug Misuse, Parts 1 and 2* (London, 1988 and 1989).

31 J. Strang, 'A model service: turning the generalist on to drugs', MacGregor (ed.), *Drugs and British Society*, 143–69.

32 Home Office, *Prevention*.

33 H. Shapiro, 'Press review July 1980–May 1981', *Druglink*, 16 (1981), 6–8.

34 N. Dorn, 'Media campaigns', *Druglink*, 1, 2 (1986), 8–9.

35 J. Jaffe, 'Drug addiction: the American experience', Okey memorial lecture, Institute of Psychiatry, 1986. Key figures were Dr John Strang, regional consultant in Manchester, Dr Dorothy Black, senior medical officer at the Department of Health and Dr Philip Connell, chairman of the Advisory Council on the Misuse of Drugs.

36 J. F. Peutherer, E. Edmonds, P. Simmonds, J. D. Dickson *et al.*, 'HTLV-III antibody in Edinburgh drug addicts', *Lancet*, 2 (1985), 1129; J. R. Robertson, A. B. V. Bucknall, P. D. Welsby *et al.*, 'Epidemic of AIDS related virus (HTLV-III/LAV)

infection among intravenous drug abusers', *British Medical Journal*, 292 (1986), 527.

37 Berridge and Strong, 'AIDS policies in the UK'.

38 Scottish Home and Health Department, *HIV Infection in Scotland. Report of the Scottish Committee on HIV Infection and Intravenous Drug Misuse* (Edinburgh, 1986).

39 D. Turner, 'AIDS and injecting', *Druglink*, 1, 3 (1986), 8–9.

40 R. Newcombe, 'High time for harm reduction', *Druglink*, 2, 1 (1987), 10-11.

41 Department of Health civil servant, observation to author, 1986.

42 Dr Dorothy Black speaking at Hatfield Polytechnic conference, June 1989.

43 DHSS, *AIDS and Drug Misuse Part I* (London, 1988).

44 G. Stimson, L. Alldritt, K. Dolan, M. Donoghoe and R. Lart, *Injecting Equipment Exchange Schemes – Final Report* (Goldsmiths' College, Monitoring Research Group, 1988).

45 Dr Dorothy Black, conference paper, June 1989.

46 Stimson, 'AIDS and HIV'.

47 See speech by Chris Butler in House of Commons Debate on Drug Abuse, *Hansard*, 9 June 1989, cols. 470–4.

48 M. Wolf, 'Thinking about drug legalisation', *Financial Times*, 4 September 1989.

49 For example, an evaluation of Liverpool's 'prescribing' clinic found its actual practice little different from 'non-prescribing' clinics. See C. Fazey, *An Evaluation of Liverpool Drug Dependency Clinic. The First Two Years 1985 to 1987* (Liverpool, 1988).

50 Interview, drug consultant, January 1989.

51 B. Pimlott, paper on 'Thatcher: the first ten years' (Conference, London School of Economics, 1989).

52 Interview, drug consultant, January 1989.

53 Berridge, 'Drugs and social policy'. Alcohol and drug policy has long been an interesting example of the relationship between medicine and the state. See R. M. MacLeod, 'The edge of hope: social policy and chronic alcoholism, 1870–1900', *Journal of the History of Medicine and Allied Sciences*, 22 (1967), 215–45.

54 'HIV top priority, says official report', *Druglink*, 3, 3 (1988), 6.

55 Berridge and Edwards, *Opium and the People*.

56 MacLeod, 'The edge of hope'.

57 J. Lewis, *What Price Community Medicine? The Philosophy, Practice and Politics of Public Health Since 1919* (Brighton, 1986).

58 For similar comments from a sociological perspective, see G. Stimson and R. Lart, 'HIV, drugs and public health in England: new words, old tunes' (unpublished paper).

59 C. Smart, 'Social policy and drug addiction: a critical study of policy development', *British Journal of Addiction*, 79 (1984), 31–9.

60 Berridge and Edwards, *Opium and the People*.

61 See the Report of the Drug Addiction Research Initiative and N. Dorn, 'The agenda for prevention', in V. Berridge (ed.), *Drugs Research and Policy in Britain: A Review of the 1980s* (Aldershot, 1990).

62 R. Smart, 'A comment on the "Syringe Exchange Schemes Final Report"', *British Journal of Addiction*, 84 (1989), 1289–90.

63 Senior Conservative politician. Comment at private meeting, 1989.

64 House of Commons, Third Report from the Social Services Committee. Problems Associated with AIDS. Volumes I–III. *Report, Proceedings of Committee and Minutes of Evidence* (London, 1987).

65 U. Padel, 'Fair trial for justice proposals', *Druglink*, 5 (1991), 6–7.

66 T. Harding, 'HIV infection and AIDS in the prison environment: a test case for the respect of human rights', in J. Strang and G. Stimson (eds.), *AIDS and Drug Misuse. The Challenge for Policy and Practice in the 1990's* (London, 1990), 197–207.

67 Rolleston Report, *Report of the Departmental Committee on Morphine and Heroin Addiction* (London, 1926).

68 Berridge and Edwards, *Opium and the People.*

69 M. Rose, 'The success of social reform? The Central Control Board (Liquor Traffic) 1915–21', in M. R. D. Foot (ed.), *War and Society* (London, 1973).

70 Berridge, 'Drugs and social policy'.

71 In Scotland, the role of the pharmacist in the prevention of HIV spread has been important. There are parallels with the nineteenth-century role of the pharmacist in dispensing opiates and providing medical care to poor clients. See Berridge and Edwards, *Opium and the People.*

8

The New York needle trial: the politics of public health in the age of AIDS

WARWICK ANDERSON

In January 1988 Dr Stephen C. Joseph, the New York City Health Commissioner, gained approval from the state health administration for a medical experiment, a controlled clinical trial. Usually the conduct of a clinical trial is respectfully left to experts; rarely will its origins be announced on the front page of the *New York Times*, with its fortunes chronicled in subsequent editions. But this was no ordinary scientific trial. Law enforcement officials immediately called the experiment 'unthinkable', and many of the city's minority leaders denounced it as 'genocide'. The trial was designed to recruit a limited number of drug addicts to a treatment group permitted to trade-in used needles and syringes for sterile equipment, and to compare their progress with a control group not given the same access to clean paraphernalia. From the beginning, New York's experimental needle exchange scheme, like so many other public health initiatives aimed at controlling HIV infection, was controversial, a focus for fear, frustration and political manoeuvre in the city. The troubled history of the needle exchange scheme illustrates the constraints on health promotion in a liberal American city overwhelmed by AIDS, drug addiction and racial tension.

Although it has recently been argued that the development of AIDS policy offers 'many examples of the triumph of the ethic of professionalism over the confused and conflicting claims of morality and ideology', the attempt to establish a needle exchange scheme in New York is not such an instance. Here there was no broad agreement about policy, or who was in charge of it; no 'reassertion of the authority of conventional medical and public health leaders' occurred in this case.[1] Instead, the attempt to explain and to legitimate a needle exchange scheme revealed the limits of the health professionals' power in the city. Neither their institutional authority nor their access to the expertise and rhetoric of medical science ever allowed them to control the course of the debate.

This is only one incident in the response to AIDS in New York City, but it is a telling one. For the historian and for the social critic, AIDS serves, in Rosenberg's words, as 'an extraordinarily useful sampling device' that illuminates 'fundamental patterns of social value and institutional practice'.[2]

Weeks, too, has pointed out that conflicting social possibilities shape the ways in which we interpret illness and therefore organise the ways in which we respond. 'What gives AIDS a particular power', he suggests, 'is its ability to represent a host of fears, anxieties and problems in our current post-permissive society.'[3] The methodological point has become commonplace, but rarely have its adherents provided us with the detailed and provocative social history one might expect. Indeed, for many of the more contemplative social analysts of AIDS, the epidemic has seemed principally an opportunity for historical analogy and sociological apriorism, an event apparently detached from the conditions of contemporary human suffering.[4]

My account of the social challenges of intravenous drug use and HIV infection in New York City focuses on the strategies that public health officials employed in order to legitimate a needle exchange. In Europe and Australia, the organised exchange of drug paraphernalia from the start met with considerably less opposition – with less ethnic hostility in particular.[5] Public health officials were able to 'sell' such exchanges as unpleasant but probably effective mechanisms for harm-reduction, and then conduct further research on the relatively 'user-friendly' programmes. But in New York City a pilot needle exchange scheme, in order to have even a remote chance of acceptance, was packaged from the start as a controlled clinical trial, as a scientific experiment.

Health professionals – arguing that a rigorous scientific assessment of needle exchanges was still necessary – attempted to overcome contention and deflect responsibility for a controversial decision by invoking the 'objective' process of the clinical trial, and so represent their actions as a 'scientific' response to the crisis. Advocates of needle exchanges had reached a stalemate with the promoters of law enforcement, and the use of clinical science to structure public policy – a policy which in another political context would have been more pragmatic – seemed to offer a solution. That health professionals should seek a recourse both scientific and polemical to the clinical trial is not surprising. In this century, the controlled clinical trial has replaced anecdotal evidence as the irreproachable standard for evaluating and representing new medical intervention.[6] But the use of such a restrictive research process in part to secure a broad political consensus on public policy, as in this case, raises some difficult ethical questions – or, rather, it should have.

The conduct of a clinical trial requires constant vigilance to ensure that an effective treatment is not withheld from any untreated group during the course of the test. In order to establish and continue a clinical trial, the physician must be able to make an 'intellectually honest admission that the best therapy is not known'.[7] Fried has called this state of genuine uncertainty about effective therapy investigator 'equipoise'.[8] It is, of course, a condition often aimed at, but rarely attained. The clinical investigator's failure to achieve equipoise has frequently appeared to present an obstacle to the ethical commencement or completion of a clinical trial. To overcome the ethical objection, Freedman has recently suggested the concept of 'clinical equipoise'.[9] According to this theory the ethical requirements for a clinical trial are met so long as there is genuine uncertainty within the expert medical community about the preferred intervention. But by late 1988, that part of the medical community whose expertise lay in the study of disease prevention and public health – the experts who would design and analyse any trial – could be reasonably sure that providing clean needles to intravenous drug users was one of the few interventions that might slow the transmission of the human immunodeficiency virus and improve outreach education, without encouraging addiction. By then, European and Australian studies (although no North American ones) offering evidence of these outcomes could be cited – as indeed they frequently were.

On the face of it, the rapidly improving scientific understanding of the subject that occurred during 1988 would make the maintenance of equipoise among the investigators, or in the relevant medical community, quite challenging. Yet, at the same time, the only politically acceptable, and practically efficacious, way to distribute clean needles in New York City was by representing the intervention as a controlled clinical trial, and setting aside consideration of any potential ethical infractions. The efforts to establish the New York needle exchange trial thus illustrate some general problems for AIDS prevention: this commentary on recent events in New York examines the practical limitations on health promotion, the use (under constraint) of a restrictive research process to organise public policy, and the ethical hazards of health professionals seeking a polemical recourse to the clinical trial.

Public health or law enforcement?

Dr David Sencer, then New York City's Health Commissioner, had first proposed the pragmatic distribution of clean needles to drug users in September 1985. By refusing them access to clean needles, he said, 'we are condemning large numbers of addicts to death from AIDS'.[10] But the recommendation provoked vehement opposition. Law enforcement officials argued that addicts were not responsible enough to use clean needles to safeguard their own health: making needles freely available would appear to condone addiction and only encourage young people to try drugs. One of the plan's principal opponents, Sterling Johnson Jr, the special narcotics prosecutor in the Manhattan District Attorney's office, wrote an impassioned letter to the Mayor. 'Drug addicts,' he advised, ' in the frenzied and desperate minutes before injecting a needle into their veins, could not care less about contamination.' Experience had taught him that 'slaves of addiction do not change their daily habits'.[11] Within a few days, Mayor Koch had rejected Sencer's recommendation, observing wryly that the idea was obviously one 'whose time has not come and, based upon the response, will never come'.[12]

By late 1985, over a million Americans had been exposed to the human immunodeficiency virus (HIV). The number of cases of AIDS was doubling each year. Almost 30% of the 4,387 cases reported in New York since 1981 were IV drug users, and increasingly the experts feared that this group would transmit the virus to their spouses and children, passing the disease into the general community. Yet the prevention of HIV infection among drug users, who were mostly African-American and Hispanic, had scarcely begun. All through the summer of 1985, city officials had been working to persuade homosexuals to avoid the bathhouses.[13] They were also engaged in a debate with angry parents in Queens who were trying to exclude children with AIDS from the schools. The Schools Chancellor and health officials attempted to reassure parents, promising them that all classrooms would have supplies of alcohol swabs and rubber gloves.[14] But no specific measures were taken to reduce the spread of the virus among drug users: there was, instead, a vague hope that an expansion of drug treatment programmes might take care of the problem.[15] Of the approximately 250,000 IV drug users in New York City, only 30,000 received treatment, and 1,500 were on the waiting lists.

At the time there was only one model of a successful needle exchange project. A year earlier, the Amsterdam municipal health service, at the prompting of an association of drug users (the Junkies' Union), had set up a needle and syringe exchange scheme in order to combat the spread of the hepatitis B virus. The clients of the exchange received one needle and syringe for each set they returned; the procedure was anonymous; and it was popular among the user community. Indeed, during 1985 over 100,000 needles and syringes were handed out. It provided opportunities for educational outreach, counselling and the distribution of condoms. Although clients were encouraged to stop injecting or to stabilise their habits with methadone maintenance, the approach generally was pragmatic rather than moralistic. 'If it is impossible to cure an addict,' wrote a promoter of the project, then 'one should at least try to create a situation that greatly reduces the risk that the addict harms himself or his environment.'[16]

During 1986, news of the Amsterdam scheme began to spread. A growing awareness of the dangers of HIV infection among drug users prompted an international conference sponsored by the World Health Organisation to conclude that 'initiatives of this kind could have an important role to play in stopping the spread of HIV'.[17] The Institute of Medicine of the National Academy of Sciences, in its report *Confronting AIDS*, discussed the Amsterdam project and suggested that it was time 'to begin experimenting with public policies to encourage the use of sterile needles and syringes by removing legal and administrative barriers to their possession and use'.[18]

In May 1986, the New York State Health Department and the Milbank Memorial Fund sponsored an international conference in Manhattan to assess the impact of AIDS on public policy. Many of the delegates discussed the need for needle exchanges. Dr Frederick Robins, the former president of the Institute of Medicine, admitted it was a difficult issue 'but it seems to me that the time has come to seriously consider providing needles and syringes to drug users to avoid the necessity of using common instruments'. His opinion was confirmed by Dr James Curran, the director of the AIDS programme at the National Center for Disease Control, who offered his support for a test programme. 'I would not discount anything in trying to combat this disease', he continued. 'The problem we face is bigger than politics.'[19] But Mayor Koch again declared himself against the idea. 'How can I support something that the police and law-enforcement leaders are totally against?'[20] Dr David Axelrod, the State Commissioner of Health, also expressed his opposition to making needles and syringes more widely available, for he feared that this could lead to an increase in drug addiction. Yet Dr Julian Gold, a member of Australia's national AIDS task force, reported that needles and syringes were now freely available to drug addicts in Sydney, and drug addiction had not increased.[21] Andrew Moss, from the Department of Epidemiology at University College of San Francisco, reflected on the opposition to needle exchanges:

> You cannot legalize use here. It's politically impossible. It's been brought up in many jurisdictions, and uniformly gets squelched by mayors or attorney-generals or police chiefs. But you can do it in Europe, it's being done in Holland . . . We could go and look at them and find out how it works. If it's found to be successful, then we can come back and fill a huge gap in our own public policy discussions about this issue here.[22]

Needle exchange or scientific experiment?

During 1987, the city's new Health Commissioner, Dr Stephen C. Joseph, announced that the number of AIDS-related deaths among IV drug users was probably 1,000 more than reported. He also estimated that, over the next year, nearly 800 babies infected with HIV would be born in the city, virtually all of them born to mothers who were IV drug users. The Health Department predicted that by the end of 1991 there would be at least 40,000 AIDS cases in New York City and close to 30,000 deaths. Each year IV drug users would make a larger contribution to these figures.[23]

The *New York Times* had recently published a number of articles describing European needle exchange schemes. One of these reported that the Scottish Committee on HIV Infection had recommended that free clean needles and syringes should be provided to IV drug users. After a crackdown on drug paraphernalia had forced Edinburgh's addicts to share dirty needles, the city recorded the highest infection rate in Britain, mostly among drug users. In contrast, Glasgow, with no similar needle restrictions, had nearly twice as many drug users but far fewer AIDS cases. 'The gravity of the problem', the Scottish Committee declared, 'is such that on balance the containment of the spread of the virus is a higher priority in management than the prevention of drug misuse.'[24]

The same concern was expressed elsewhere in Europe, fuelled by grim statistics. In Italy, it was estimated that more than half the 100,000 addicts were HIV positive; in France, the incidence of infection was probably 30%. Several countries were now prepared to try the Dutch model. Britain had decided to allow the exchange of needles and syringes in more than ten cities. The Swiss government permitted pharmacies to sell syringes to anyone who wanted them. In France, drug users could exchange needles and syringes in pharmacies.[25]

Yet, as the *New York Times* pointed out in an editorial, little had been done in the US to control HIV infection among drug users. In 1987, some 50% to 60% of New York's 200,000 heroin users were believed to be infected. And still there were long waits for methadone maintenance clinics and drug-free rehabilitation programmes. In the 'shooting galleries', meanwhile, addicts continued to rent and share dirty needles. Although dispensing clean needles might retard the transmission of HIV, law enforcement officers would resist on principle even 'experiments' to test the possibility.[26]

But when Dr Stephen Joseph, the city's Health Commissioner, proposed such an experiment, his chief critics initially were state health officials, who faulted the trial on technical grounds.[27] Dr Joseph had suggested that the city should dispense clean needles and syringes to several hundred addicts who were not HIV positive and who were waiting the many months it took to join a methadone maintenance programme. An identical control group, addicts not given clean needles and syringes, would also be monitored to assess behavioural change and to measure relative rates of infection. This would be the nation's first trial of a needle exchange. But the proposed experiment did not satisfy the state's scientific requirements. State health officials doubted that the applicants for methadone programmes were a truly representative sample of drug addicts; and the demonstration would, in any case, have to enrol several thousand addicts to provide scientifically valid results. Dr Joseph, contending that AIDS infection among drug users was a major threat to the city's health, promised he would come up with a revised, more rigorous, trial.

The least controversial policy, though, remained a 'war on drugs'. Citing a 'state of emergency', city and state officials in June announced a new programme that would provide treatment for another 3,000 of New York's estimated 225,000 IV drug users.[28] The new clients would join the 30,000 people already enrolled at the city's 100 methadone clinics. But city officials, fearing neighbourhood opposition, declined to give the proposed addresses of the new clinics, except to say that most would be located in parts of Harlem and Brooklyn that have high rates of addiction. Evidently, there was no policy that would not incite some opposition.

Saying no to pragmatism

In the midst of a crackdown on illicit drug use, there seemed no acceptable camouflage for any pragmatic schemes that made it safer to inject drugs. But, in January 1988, the issue was forced. A community action group, the Association for Drug Abuse Prevention and Treatment (ADAPT), decided to defy state law and distribute free needles and syringes in the city. ADAPT was a private, non-profit group, formed in 1980 to counsel addicts to stop using drugs and enter treatment. It was based in Brooklyn, and relied on donations and grants to support its ten full-time staff members, most of whom were ex-users or sympathetic outreach workers. Unlike similar organisations in Amsterdam and Australia, current users were not active in its leadership.[29] The president of ADAPT, Yolanda Serrano, told the press that her agency was prepared to face prosecution in order to 'protect the public and save lives'.[30]

Dr Joseph praised the group's commitment and responsibility, but felt that he could not condone this illegal action. 'It's regrettable', he said, 'that the issue has come to a head in this way, when it's scientifically uncontrolled.'[31] Sterling Johnson condemned the plan more vehemently. He speculated on whether it might be a prosecutable offence; perhaps there were even grounds for a criminal charge of homicide if an addict overdosed using one of the clean needles. But Ms Serrano thought the risks of the project were overstated. New York was one of eleven states restricting needles, yet it had the highest rate of drug abuse in the country. In any case, ADAPT intended to give clean needles only to those who already had dirty ones. It was too late, Ms Serrano declared, to engage in the research process. 'Something has to be done now. Someone has to take the initiative to challenge the state in the name of public health.'[32]

Dr Axelrod refused to comment on ADAPT's plans, but pointed out that the state was still considering a revised experimental needle exchange. Mayor Koch said that the law must be obeyed, though he would favour a limited experiment at some stage. 'I have an open mind', Governor Cuomo was reported as saying, adding that the issue has been 'tormenting me – it's very, very difficult'.[33] But not everyone encountered the same difficulties. The Surgeon-General, C. Everett Koop, mentioned at the launching of an information brochure on AIDS that needle exchange schemes would be worth considering, even though they faced public resistance. 'With a fatal epidemic, that's spreading as this one is, you do anything in the world that you can do to stop it', he said. 'And if providing free needles will stop it, that's fine.'[34]

The clinical trial

Three days later, the Cuomo administration announced that it would let New York City conduct a revised clinical trial of needle and syringe distribution. State and city health officials stressed that the plan, the first time in the US that a government would provide drug paraphernalia to addicts, was a scientific experiment, and it would be discontinued if it failed to retard the spread of AIDS. Dr Axelrod had previously opposed the idea of a needle exchange, arguing that addicts' behaviour was so unpredictable that it would be impossible to monitor the programme. But now he was confident that the trial in its revised form could produce scientifically valid results.[35]

The New York study initially would involve 400 IV drug users awaiting rehabilitation. At this stage, Joseph proposed to draw addicts from targeted neighbourhoods, rather than from the whole city, in order to make the experiment easier to manage. The participant would be issued with an identification card, with a photograph and fingerprint on it, then enter the treatment group or the control group depending on the site attended. All subjects were to receive counselling and general medical assistance. The proposal called for the randomisation of the sites where the programme was offered, rather than the randomisation of individual subjects. Anyone who had enrolled in a control site would be free to withdraw and then re-enrol at a treatment site, though this may mean travelling across town. No one had yet worked out how to entice the control group back for regular monitoring; and no one could discern any obvious endpoint for the study. But since the average waiting time to enter a methadone maintenance programme was one to three months, and six months to get into a drug-free programme, the problem of finding an endpoint seemed unlikely to arise.

Law enforcement officers and drug rehabilitation experts soon found fault with the plan. To representatives of the law, and conservative politicians, the very idea was inimical, even in the guise of medical science. 'It sends out the message that it is right to shoot drugs', declared Sterling Johnson. 'It may be well meaning, but I think it is a very bad mistake.'[36] The State Assembly's Republican minority went on record unanimously to oppose any needle exchange scheme. The minority leader, Clarence Rappleyea, stated that: 'The notion of state-subsidized drug abuse is abhorrent.'[37] The Catholic church also opposed the scheme: Cardinal O'Connor accused the city of 'dragging down the standards of all society'.[38]

Managers of drug treatment programmes criticised both the design of the trial and its principles. Many such as Dr Beny J. Primm, the director of the Addiction Research and Treatment Corporation, feared that distributing needles would become a cheap substitute for rehabilitation. Dr Robert Newman, the president of Beth Israel Medical Center, the largest provider of methadone maintenance programmes in the city, said he supported the idea of a needle exchange scheme, but wondered how communities that resisted drug treatment centres would react to practising addicts appearing regularly to pick up their needles and syringes. Few of these experts could see how the experiment could come up with any meaningful scientific conclusion. According to Dr Mitchell Rosenthal, the president of Phoenix House, the chief provider of drug-free rehabilitation in New York, addicts were 'the most disordered people in society', hardly likely to travel across Manhattan to register for an identification card.[39] This debate focused on the scientific legitimacy and the feasibility of the experiment: no one questioned the ethical aspects of not providing clean needles to a control group, or asked if a clinical trial was the best way to deal with a public health crisis.

'They don't want to give out free needles . . . '

But the idea of distributing clean needles and syringes, one way or another, did have its non-medical supporters – only they were often difficult to find. Thomas Morgan, a reporter with the *New York Times*, ventured into a 'shooting gallery' to talk to some of them.[40] There, in an abandoned building near the Williamsburg Bridge in Brooklyn, he met a man who called himself Cano, 'the man with the needles'. A packet of ten syringes, illegally acquired, cost him $4, he said, and he sold them to others for $2 each to support his heroin and cocaine habit. 'People are buying them a lot because they don't want to share', he said. 'People are afraid of AIDS.' In the dim glow of the candles, Morgan also talked to a thirty-two-year-old man called Willenski who was fidgeting as he awaited his turn. 'This talk about addicts liking to share needles is a lie', he said. 'They don't want to give out free needles because they want us to die, and they see it as a good way to get rid of us.'

Since 1984, ethnographic studies in New York City had suggested that addicts knew about AIDS and had taken steps to protect themselves. Drug users have an addiction and a culture that make risk reduction difficult: there is a deep mistrust of the outside world, a refusal to share needles can endanger personal relationships and an addict keeping clean injection equipment runs the risk of arrest. Yet, when fifty-nine patients were interviewed at a Manhattan methadone maintenance clinic, 93% knew that sharing needles could spread the disease, 59% reported having made behavioural changes to avoid AIDS, 31% used clean needles more often and 29% had reduced needle sharing.[41] Further studies indicated that blacks were significantly more likely than other groups to report that they had decreased the sharing of works with other IV drug users: 48% compared to 26% of whites and 23% of Hispanics.[42] Des Jarlais and his colleagues observed, though, that 'the extent of increased use of new needles would depend not only on the person's general intention to avoid sharing needles but also on market supply mechanisms for providing new needles at the appropriate times'.[43] Outreach workers reported that the illicit market in New York for sterile needles had in fact expanded greatly, though perhaps not enough, since AIDS began. The threat of disease had even helped advertising. 'Get the good needles, don't get the bad AIDS', one seller chanted.[44]

Through the summer of 1988, the debate continued. The increasing severity of the AIDS problem led more health professionals to push for a needle exchange scheme. Dr Mervyn Silverman, president of the American Foundation for AIDS Research, was reported in the *New York Times* in June as saying: 'I never heard of anybody starting drugs because needles were available or stopping because they couldn't find a clean one.'[45] With needle sharing now the leading means of HIV transmission in New York, Kathleen Oliver, the head of Outside-In, a private social service agency, thought that distributing clean needles was the sensible thing to do. By refusing to provide needles and syringes, 'what you're really saying is these people are expendable, that you'd rather have them die of AIDS than give them needles'.[46]

Don Des Jarlais pointed out that in foreign cities where pragmatic needle exchanges had operated for many years now, no one could detect any rise in drug addiction. Recent evidence from Amsterdam, where 700,000 needles were given out over the previous year, implied that some addicts injected less frequently, or decided to enter treatment programmes after counselling.[47] These findings were supported by preliminary studies in Sweden, England, Scotland, France and Australia, countries where pragmatic distribution of drug injection equipment was permitted.[48] Yet it would probably take more years of observation to confirm that needle exchanges actually slowed the rate of seroconversion.

But was it advisable to wait for further gains in scientific assurance?[49] Recent studies indicated that each year about 6% of IV drug users in New York City who were not formerly infected became HIV positive.[50] Before long, the prevalence of HIV infection might rival the 80–95% figures for hepatitis B infection found among drug users in New York and San Francisco. Even in late 1987, a survey had shown that one of every sixty-one babies born in New York City carried antibodies to HIV, with most of the affected babies born in poorer neighbourhoods.[51] With a public health disaster looming, needle exchange programmes were now proposed in Boston, the District of Columbia, New Jersey and San Francisco, as well as New York. San Francisco had been distributing bleach and telling addicts how to sterilise needles for over a year.[52] The Vancouver health authorities, convinced of 'the success of needle exchange programs and, in particular, that such programs clearly did not encourage new drug users', had recently 'sold' the idea of a pragmatic scheme in their city.[53] In New York, though, the search for more 'conclusive' scientific evidence was just about to begin.

A pilot programme

In February, Dr Joseph had told Peter Kerr, a reporter from the *Times*: 'We shouldn't delude ourselves. It is not a static situation. We don't have that much time.'[54] But ten months later, Joseph's proposed experiment was still not operating. As the months passed, even the tentative plans had been scaled down.

Predictably, no neighbourhood wanted a needle exchange anywhere near it. Dr John V. Natoli, the principal of Public School 33 in Chelsea, was incensed when he heard that a needle exchange would soon open next door. 'I have no objection to the program as an experiment', he said, 'but as an educator, I don't see how you can place such a facility right next to a school.'[55] He was worried that the area would become littered with used needles. Dr Joseph, though, pointed out that the Chelsea centre already did HIV testing, so 'hundreds if not thousands' of addicts passed the school every day. He believed the pilot programme was under siege from critics 'not because of any actual harm it could cause, but because it symbolizes the worst fears of its detractors'.[56] But Mayor Koch stepped in and cancelled the plans for neighbourhood exchanges. Since Koch's decision suddenly meant that only one site was available, the proposal for a randomisation of sites had to be abandoned just a few days before the start of the trial.[57] Now all subjects would have to travel across town to the Health Department's headquarters in lower Manhattan.

The 'clinical trial' began on 7 December 1988, three years after David Sencer had first suggested the distribution of clean needles, and after two years of planning and redesign. The New York State Health Department's institutional review board had approved the new proposal, and the state Health Commissioner had finally promulgated the necessary regulations identifying the persons authorised to obtain or furnish hypodermic syringes (10 NYCRR section 80.134). But the trial was now called a 'pilot study' and seemed less consequential than ever. Most likely, it would simply determine whether drug addicts could comply with the conditions of a clinical trial, though it might still provide some information on how effectively a needle exchange scheme slowed the spread of HIV infection. According to Don Des Jarlais, for a large-scale trial to be feasible, the pilot study would have to attract enough volunteers, who would have to exchange regularly their used needles for clean ones, and be prepared to enter drug treatment programmes when vacancies occurred. Another important criterion of success was community support for the experiment.[58]

The number of IV drug users that could be enrolled was still limited to 400. To participate, addicts eighteen years and older had to register at the Health Department's headquarters in lower Manhattan, where they would be interviewed and examined by doctors, sign consent forms and be tested for tuberculosis, sexually transmitted diseases and HIV infection. These tests were to be repeated regularly throughout the trial. Only drug users who had applied to a drug rehabilitation programme and had been turned away because it was full were eligible for the study. When they came in to register they had to show a letter of referral from the programme.[59]

Participants could exchange injection equipment between 10 a.m. and 3 p.m., Monday through Friday at the lone distribution site in downtown Manhattan, where they also received counselling and education. Each participant had an identification card with a photograph attached, to prevent others from getting access to the clean needles. Furthermore, the researchers planned to check the returned needles and syringes to make sure the blood in them was the same type as the participant's. If it was not, the participant would be warned, but no one had decided yet how many warnings were allowed before the refractory needle sharer had to be dropped from the study.

The initial proposal had included non-exchanging sites where members of a 'comparison group' would also receive counselling, bleach kits and basic medical assessment, but not injection equipment. This was to allow researchers to make statistical comparisons of behavioural changes and HIV infection rates between the 'treated' and 'untreated' groups.[60] But Koch's sudden decision to restrict the trial had thrown plans for a control group into confusion. Des Jarlais suggested using an historical control, consisting of drug users that his group had been following for some years.[61] Eventually, though, a 'comparison group' was found in the South Bronx. The needle exchange's staff gained access to a clinic where they counselled the patients who injected drugs. Sixty-one patients decided to 'pre-enrol' in the programme, that is they 'completed all aspects of the enrolment procedure although they were unwilling to travel from the South Bronx to 125 Worth St to receive an ID card and hypodermic equipment'.[62] This became the 'comparison group' which was followed for relative rates of needle sharing, and seroconversion.

'Encouragement of drug abuse'

Only two people had enrolled by the end of the first day of the experiment. They first had to pass the barricades that police had erected in anticipation of protests against the scheme. In fact, by 10 a.m. only twenty demonstrators had gathered outside the Health Department, most of them from ADAPT, chanting slogans like: 'Free needles save lives.' The poor response from IV drug users did not surprise the demonstrators. Several of them pointed out that the single distribution centre was inconvenient, with limited hours. Others observed that the study required addicts to identify themselves to a government agency.[63] Only eight applicants had shown up by the end of the week.

Meanwhile, criticism of the study became more vehement. Rarely, though, did critics bother any longer to challenge the scientific validity of the small, constrained trial, which even its promoters now seemed to assume was negligible. Instead, its opponents – including prosecutors, the police, black and Hispanic politicians and operators of drug treatment programmes – expressed their concern that the government appeared to sanction IV drug use. The distribution of clean needles and syringes seemed to them a cynical, cheap solution to a drug problem that had brought not only AIDS but also crime, social breakdown and other illnesses – such as tuberculosis – to the city's black and Hispanic neighbourhoods. A new sign was posted on lampposts in Harlem: 'When will all the junkies die so the rest of us can go on living?'[64] The Police Commissioner, Benjamin Ward, told the *New York Times*: 'As a black person, I have a particular sensitivity to doctors conducting experiments, and they too frequently seem to be conducted against blacks.'[65] The New York City Council voted overwhelmingly to approve a non-binding resolution calling on the Koch administration to abandon the pilot needle exchange project. Enoch Williams, the chairman of the Council's black and Hispanic caucus, argued that 'The city is sending the wrong message when it distributes free needles to drug addicts while we are trying to convince our children to say no to drugs.'[66] According to City Councilman Hilton B. Clark of Harlem, needle distribution was 'genocide' and the programme's architect, Dr Stephen C. Joseph, 'should be arrested for murder and drug distribution'.[67]

In response, Yolanda Serrano from ADAPT exclaimed: 'They talk about genocide – this is the real genocide. People can survive addiction, but they can't survive AIDS.'[68] Dr Joseph tried to calm things down and distance himself from the dispute: 'People are taking positions based on opinions and assumptions without any data, and that's what we want to get.'[69] But this appeal to the 'objectivity' of medical research seemed no longer convincing enough to dissolve the controversy.

During January, in another interview with the *Times*, Joseph agreed that 'It obviously has been a very tough row to hoe because of constraints placed on the program and the intensity of opposition to it.'[70] After two months, only fifty-six addicts had enrolled, and only seventy-six needles had been dispensed. Health officials decided to alter the experiment so they could concentrate more on getting drug users into rehabilitation programmes. Joseph conceded that the number of addicts so far enrolled would be too few to draw any valid 'scientific' conclusions.

For the last five months on a street corner in Tacoma, Washington, just a few steps from a 'shooting gallery', David Purchase had successfully handed out clean syringes in exchange for used ones. His volunteer efforts proved more popular than the New York 'experiment' – 13,000 needles had already been exchanged – even though fewer than 3,000 IV drug users lived in Tacoma. Purchase, a forty-nine-year-old drug counsellor disabled from a motorbike accident, told reporters that needle exchanges elsewhere had been hampered by 'ignorance, politics and moral fascism'. He believed that if dispensing clean needles and syringes turned out not to slow the spread of HIV infection, then he would just look foolish, but if those who blocked needle exchanges were wrong, 'their children will be dead'.[71] In Tacoma, Purchase had the support of the local Police Chief, who suspended enforcement of the law on possession of drug paraphernalia. But at the same time in Boston, a similar volunteer effort met a different fate, and the distributor was arrested. Another proposal to distribute clean needles, from a private social service agency in Portland, Oregon, was being delayed by insurance problems.[72]

Uncertain policies

In early 1989 the government response to AIDS in New York City was fragmented, contentious and inadequately funded. Koch and other city officials blamed state agencies for cutting reimbursements to AIDS patients, failing to expand hospitals and stalling on clinics to treat drug addiction. State officials, in turn, attacked the city for neglecting public hospitals and shirking on drug treatment. Axelrod, the State Health Commissioner, was confronted with extraordinary overcrowding in the hospitals and nursing homes he was responsible for. His city counterpart, Joseph, had antagonised minority politicians with his promotion of a needle exchange programme and recently upset AIDS advocacy groups when he reduced the estimate of the number of New Yorkers infected with HIV.[73]

During that spring, a number of federal officials commented on the needle exchange experiment, initially in support of it. The National Research Council, the research division of the National Academy of Sciences, produced a report on the national response to AIDS. To reduce the spread of HIV infection among IV drug users, the committee recommended an expansion of needle exchange programmes.[74] Dr Louis W. Sullivan, President Bush's new Secretary of Health and Human Services, also endorsed needle exchange schemes. 'I don't subscribe to the view that it condones drug abuse', he said. 'It is an idea that certainly deserves some investigation to see if it does work.'[75] But Representative Charles B. Rangel, a Manhattan Democrat who headed the Select Committee on Narcotics Abuse and Control, immediately condemned Sullivan's comments, calling them 'tragic, ill-advised and illegal'. Needle exchange programmes, he declared, 'would keep addicts out of sight, out of mind, and sweep them under the rug instead of restoring their dignity and giving them drug-free lives'.[76] Don Hamilton, a spokesman for William J. Bennett, the head of the Bush administration's anti-drug efforts, told the *New York Times* that needle exchange schemes were ineffective and, since they were likely to encourage drug abuse, also 'pernicious'.[77] Marlin Fitzwater, the President's spokesman, assured the press that 'The President is opposed to the exchange of needles under any condition.'[78] When asked about the apparent conflict, Campbell Gardett, a spokesman for Dr Sullivan, said 'We're in an in-between period when an awful lot has to be worked out.'[79]

So the confusion over US needle exchange policy continued. In Europe and Australia the distribution of needles and syringes had been less contentious. In April 1989, directors of AIDS prevention programmes in Britain and the Netherlands told the House Energy and Commerce subcommittee on health and the environment that providing clean needles and syringes to addicts had reduced needle sharing, without increasing drug abuse. Allan Parry, who was in charge of thirteen needle exchange programmes in the Liverpool area, told the committee that since 1986 he had not found one case of HIV infection among the 1,050 addicts that had received clean needles.[80] In Amsterdam, HIV infection among IV drug users had stabilised for two years, and new cases of hepatitis B had dropped 75%. Evidence from the only successful US exchange also suggested the project's effectiveness. According to Dr Alfred Allen, the Pierce County, WA, health director, since David Purchase began distributing clean needles in Tacoma admissions to drug treatment programmes had increased by one third. Local surveys indicated that 90% of addicts no longer shared needles. Purchase himself told the committee that he was convinced that protecting IV drug users from a fatal disease was more important than moral concerns about drug abuse. 'You can get over being stupid', he said 'but you can't get over being dead.'[81]

But after seven months, the carefully regulated New York needle exchange experiment had attracted only 160 participants. Axelrod had recently permitted the programme to accept addicts off the street, without letters of referral, but the other barriers to participation remained. Eventually, over 250 IV drug users enrolled in the programme during its first ten months, but there was still no sign that the 'data' on these subjects and on the comparison group 'will begin a new less confrontational era of AIDS prevention policy'.[82] Councilman Hilton Clark continued to argue that the programme was a failure as an experiment, and the 'data' showed nothing of any value. 'People are not participating', he said. 'We are going to call for a cessation of the program because it is still sending out the wrong message: using drugs is O.K.'[83]

A public health agenda?

The message that city health officials had hoped to send out was that the exchange scheme was a valuable scientific experiment in the prevention of HIV infection. Instead, the project was read as an endorsement of drug use. Never a popular suggestion, any hint of tolerance of addiction was, in the summer of 1989, politically unthinkable.

In September, George Bush warned that drugs were 'sapping our strength as a nation', and announced a national drug control strategy that stressed law enforcement.[84] His televised address from the Oval Office paid little attention to prevention efforts, or to the rehabilitation of addicts. Drug experts complained that neither Bush's programme nor any existing state approach provided nearly enough clinics for addicts who wanted to break the habit. According to Salvatore di Menza, special assistant to the director of the National Institute on Drug Abuse, perhaps a million addicts wanted treatment that was simply not available.[85] Many of them languished on waiting lists for eight months or more.[86] Many did not bother even signing up.

When David Dinkins became Mayor of New York, he confirmed the emphasis on the policing of drug use, appointing Nicholas DeB. Katzenbach, a former US Attorney-General, to head a study group to recommend a strategy for fighting addiction.[87] Dinkins had always opposed the needle exchange experiment, arguing that to provide addicts with needles was to give in to drug abuse. 'I think we need to go at fighting drug addiction in the first instance', he told the *Times*, 'and I don't want to give people the paraphernalia to keep using drugs.'[88] So when he announced the abandonment of the trial, in February 1990, it came as no surprise. Joseph, though, who had been replaced as Health Commissioner by Dr Woodrow A. Myers, expressed his disappointment with the decision. 'Black leadership has consistently opposed it and I think they made a big mistake', he said, 'because some people who might have survived are going to die.'[89]

At his first news conference, in April 1990, Dr Myers explained that he intended to concentrate on expanding drug treatment. He was 'ideologically opposed' to the government distribution of needles and syringes, and could not, he said, imagine any evidence that would convince him that such schemes were worthwhile.[90] Myers also felt it was not the city's responsibility to teach addicts safer injection techniques, or to give them bleach to disinfect needles and syringes. In response, Des Jarlais told the *Times* that he had reviewed needle exchange programmes in Tacoma; Portland, Oregon; Seattle; San Francisco; Britain; the Netherlands; Sweden; Australia; and Canada. He would be happy to discuss these studies with Myers. 'They are really quite clear', he said. 'Safe injection practices have not led to increased drug use, and have led to large reductions in AIDS risk behavior.'[91] Yolanda Serrano, one of the few minority officials to have supported the idea of a needle exchange, was even more blunt. She pointed out that drug treatment was not readily available, and some addicts were unwilling or unable to enter rehabilitation programmes. 'What do we do, just let them die and take their families with them?'[92]

In May, a coalition of major AIDS organisations, including the Gay Men's Health Crisis and the American Foundation for AIDS Research (AmFAR), appealed to Myers to change his opinion on the promotion of safe injection techniques. Dr David Rogers, head of the New York State AIDS Advisory Council and the Mayor's AIDS Task Force, claimed that eliminating prevention programmes was 'indefensible'. Myers's actions had left him 'absolutely bewildered'.[93] Dr Mathilde Krim, co-founder of AmFAR, said she was in favour of 'all these life-saving measures' – to be otherwise would doom many drug users and their spouses and babies as 'dispensable'.[94]

Myers also advocated withdrawing city funds from ADAPT's rather perfunctory bleach distribution efforts. The Black Leadership Commission on AIDS, a group of sixty-five doctors, lawyers, politicians and business executives, supported his stand. They accused white public health officials of being too quick to endorse cheap ways of stopping AIDS, while failing to spend enough on drug treatment. Bleach distribution contained 'a grave element of risk' to the African-American community, the Commission said.[95] But according to Mathilde Krim, their statement was 'contemptible, absurd and irrational'. The debate was polarising blacks against whites. 'The majority of whites are in favor of preventing HIV transmission by any means', she said, but blacks 'are obsessed with the demand for treatment.'[96]

Yet, in May 1990, it was John C. Daniels, the first black Mayor of New Haven, who gained his Council's authorisation of a local needle exchange scheme. He had argued that with 75% of the AIDS cases in New Haven linked to IV drug use, and over 4,000 addicts in the city, making clean needles available would keep people alive until they could be helped. Officials hoped to dispense 500 needle kits each week, and planned to expand the programme to Hartford and Bridgeport by 1992. They had decided that the needle and syringe distribution would be more pragmatic than it had been in New York. For a start, kits would be dispensed from a van travelling around the neighbourhoods where addicts lived. The programme had received enthusiastic support from New Haven's Police Chief, Nicholas Pastore. 'The 1990's is calling for some new thinking in dealing with these issues', he said. 'I like to see the Police Department's moving toward a social engineering role.'[97] Alvin Novick, a professor of biology at Yale and chairman of the Mayor's Task Force on AIDS, told reporters: 'This is not a political agenda: it's a public health agenda.'[98]

Conclusion

I have described here the history of one effort to curtail the spread of HIV among drug users. My intention, however, is not to point out the 'rational' course of action, or the 'correct' public policy. There are lessons to be learnt from this case, certainly, but they are not easily expressed in terms of right and wrong. I have tried, rather, to illustrate the contested meanings of health promotion and clinical research during the late 1980s in New York City – a diverse community facing an array of health crises and moral uncertainties. A number of groups – including public health officials, drug treatment experts, law enforcement officers, local community leaders, drug users and federal, state and city politicians – all had an interest in controlling the meaning of both the problem of HIV transmission among IV drug users and any intervention to curtail it. On a practical level, the various interpretations of the nature and severity of AIDS and illicit drug use determined each interested party's response to the needle exchange trial. The experimental programme was promoted by health professionals as the most rational and scientific approach possible in the circumstances, but undoubtedly it was seen by other groups – ultimately more influential ones – as a symbolic endorsement of illegal drug use, the major perceived threat to the integrity of the community.

The failure of the New York needle exchange illustrates a social resistance to defining HIV infection as a technical problem, and reveals local limitations on the role of expert groups in the formation of controversial policy. Invoking the prestige of medical science is not always sufficient to compel acceptance of contested policies. Indeed, the opinions of city health officials were treated with suspicion, making it difficult for them to avoid creating the impression that they were hiding political decisions in technical assessments. While evidence from abroad by early 1989 suggested that the distribution of clean needles and syringes could reduce the sharing of drug paraphernalia without increasing addiction, this evidence clearly, in the end, was outweighed by the magnitude of the policy's symbolic affront to social order. Thus the control over the definition of the relevant issues had been wrested from the health professionals and, in the end, the explicit moral and political aspects of the problem proved paramount in defining society's response.

In New York, the ineffectiveness of expert opinion that Fox detected in the initial response to AIDS was never rectified.[99] The epidemic challenged a health system increasingly preoccupied with cost containment and the decentralisation of authority. It was a fractured system poorly prepared to devise and enforce a co-ordinated and convincing programme to curtail the spread of the virus.[100] The intensity of disagreement over access to sterile injection equipment thus continues to illustrate how 'the public rhetorical dramas of symbolic politics are a mechanism for coping with the fragmentation of political authority'.[101] And at least in part, it confirms Porter's speculation that 'the appalling slowness and ineptitude of the United States response to AIDS arose out of the mixed blessings of the decentralised state and of City Hall caucus politics'.[102]

It is not surprising that Dinkins's political decision should finally have ruled out a needle exchange in any guise in New York City. Intravenous drug users in New York were too unorganised and socially stigmatised to force government action, or to enter into negotiations over the appropriate policy response. They were the city's poor, mostly African-American and Hispanic, an embarrassment to their families and communities – no one's constituency. In the past, drug treatment professionals had often claimed to speak for many addicts, but it was not necessarily in their interests to promote needle exchanges.

African-American communities had been slow to mobilise against AIDS, and when they did, the leadership usually opposed the distribution of sterile injection equipment out of a concern that it would endorse drug use and substitute for rehabilitation. The churches that traditionally had taken the major role in mobilising black communities remained strongly opposed on moral grounds to any action that appeared to condone drug use. Only ADAPT, a small group of outreach workers and past users, campaigned for access to sterile needles and syringes, but their contribution to policy negotiations remained marginal.[103]

The attempt to formulate public policy in terms of the research process – even though it failed – deserves careful study, for there is a danger that political restrictions on access to care are simply replaced by research restrictions constructed on insecure scientific grounds. As soon as the provision of needle exchanges was structured as a scientific trial in New York, a recurrent anxiety emerged among the investigators: how to identify a control group that would give the experiment legitimacy. Political constraints on needle distribution were reiterated in scientific protocols that attempted to find an untreated 'comparison group' to monitor, or simply limited the trial to the few prepared to negotiate a bureaucratic maze. The experiment, or the pilot study, was predicated on exclusion. This exclusion on scientific grounds, for research purposes, itself can be read as throwing doubt on the perceived rationality of needle exchange policy, as challenging an emerging international clinical consensus. In New York City – as in few other cities abroad – public health officials maintained an agnosticism (or equipoise) on needle exchanges, and maintained it in practice long after they were able to quote studies indicating that the distribution of clean needles and syringes in a pragmatic fashion, with counselling, would be of superior therapeutic merit to the alternative of counselling alone, or perhaps counselling with bleach distribution too. This equipoise permitted them a polemical and scientific recourse to the clinical trial, and the local credibility needed to exert an influence over events.

The tension between acceptance of pragmatic exchanges on the basis of existing knowledge, and the need to construct an acceptably limited experiment is readily apparent. Even the city Health Department's report on the trial and the comparison group referred to needle exchange as 'a promising – and necessary – intervention' in a 'health crisis', and pointed out that 'no empirical data' supported the principal arguments against such programmes.[104] In a letter to Axelrod in December 1989, Stephen Joseph described needle exchanges as an 'anti-HIV intervention already researched and adopted in many parts of the world' – though not yet 'field tested' in the US.[105] Generally, the scientists involved argued that needle exchanges needed much more local controlled field testing (just as a vaccine might need more than one field trial) and that exchanges should not yet be accepted as a standard of care[106] – yet in Europe and Australia they increasingly, in response to a crisis, were becoming so accepted. In the circumstances one might have expected at least more debate on the ethics of limiting 'treatment' to a few, or making access to it difficult for a 'comparison group', for purposes of further US research of doubtful statistical power.[107] But then again, the interests of the population from which the trial drew its participants were not well represented.

But what if the configuring of policy as a restricted trial *had* been challenged on ethical grounds? Considering the balance of forces, such an attempt to bring AIDS prevention back into the middle of the political arena would most likely have resulted not in an expansion of access to clean needles, but in the abandonment of even the limited scheme – as eventually happened, although not from a squeamishness about restricting access for research purposes. But even if the choice was therefore between rigid political control over access to clean needles and a more flexible 'scientific' control, one should bear in mind that our society has chosen to hold scientists to higher ethical standards in these matters than it demands of politicians. The issue, though, became so enmeshed in politics that no one can now say with certainty who was talking as a scientist and who as a politician: there was no room left for a relatively autonomous science. Nevertheless, when clinical science is used in an effort to attain a broader community consensus or political legitimacy for public policy – as much as to resolve a genuine clinical uncertainty – then one hopes scientists will be even more vigilant than usual in guarding against a refusal of effective treatment to an untreated population either in the trial, or outside it altogether.

Since the rejection of the formulation of needle exchange policy as a research process, even fewer IV drug users in the United States now have authorised access to clean needles and syringes.[108] Yet in Europe and Australia, needle exchange schemes continue to expand in pragmatic ways. Thus a persisting irony of this story is that when the New York experiment ended, and the few local IV drug users ever permitted access to clean needles dispersed, the real international 'experiment' on the effectiveness of needle exchange schemes had just begun: only now the majority of drug injectors in the United States will serve as the control group for the rest of the world.

Acknowledgements

I am grateful to the editors of the *American Journal of Public Health* for permission to reprint this essay in its revised form. Rosemary Stevens, Charles Rosenberg, Virginia Berridge and Elizabeth Fee made helpful comments on earlier versions of the paper.

NOTES

1 D. M. Fox, P. Day and R. Klein, 'The power of professionalism: policies for AIDS in Britain, Sweden and the United States', *Daedalus*, 112 (1989), 110–11 and 107. Until the last two decades the medical profession's role in the formulation of US drug policy had been particularly limited: considering the historical context, then, it is not surprising that the aspects of AIDS prevention strategy most closely related to drug policy are the policies least amenable to expert medical control. For an account of US drug policy, see D. F. Musto, *The American Disease: Origins of Narcotic Control* (New Haven, 1973).

2 C. E. Rosenberg, 'What is an epidemic: AIDS in historical perspective', *Daedalus*, 112 (1989), 2.

3 Jeffrey Weeks, 'AIDS: the intellectual agenda', in P. Aggleton, G. Hart and P. Davies (eds.), *AIDS: Social Representation, Social Practices* (London, 1989).

4 E. Fee and D. M. Fox, 'The contemporary historiography of AIDS', *Journal of Social History*, 23 (1989), 303–14. AIDS Social History Groups in both the UK and the US have recently attempted to remedy this problem.

5 See Berridge's paper in this volume for an analysis of the way in which scientific authority in the UK provided an acceptable and apparently rational justification for pragmatic policy change. Also, more generally, see P. Strong and V. Berridge, 'No one knew anything: some issues in British AIDS policy', in P. Aggleton, P. Davies and G. Hart (eds.), *AIDS: Individual, Cultural and Policy Dimensions* (London, 1990).

6 L. Friedman, C. D. Furburg and D. L. DeMers, *et al.*, *Fundamentals of Clinical Trials* (Boston, Mass., 1981). US Congress, Office of Technology Assessment, *Impact of Randomized Clinical Trials on Health Policy and Medicine* (Washington, DC, 1983).

7 D. P. Byar, R. M. Simon and W. T. Friedewald, *et al.*, 'Randomized clinical trials: perspectives in some recent ideas', *New England Journal of Medicine*, 295 (1976), 74–80, at 74.

8 C. Fried, *Medical Experimentation: Personal Integrity and Social Policy* (Amsterdam, 1974).

9 B. Freedman, 'Equipoise and the ethics of clinical research', *New England Journal of Medicine*, 317 (1987), 141–5. See also A. R. Feinstein, 'An additional basic science for clinical medicine. II. The limitations of randomized trials', *Annals of Internal Medicine*, 99 (1983), 544–50.

10 D. Sencer, 'Choosing between two killers', *New York Times* (hereafter *NYT*), 15 Sept. 1985.

11 J. Purnick, 'Koch bars easing of syringe sales in AIDS fight', *NYT*, 4 Oct. 1985.

12 *Ibid.*

13 R. D. McFadden, 'Cuomo and Koch reconsidering their opposition to closing of bathhouses', *NYT*, 5 Oct. 1985. See R. Bayer, *Private Acts, Social Consequences: AIDS and the Politics of Public Health* (New York, 1989).

14 D. Nelkin and S. Hilgartner, 'Disputed dimensions of risk: a public school controversy over AIDS', *Milbank Quarterly*, 64 (suppl. 1) (1986), 118–42.

15 J. Barbanel, 'To combat AIDS, Koch urges anti-drug effort', *NYT*, 17 Dec. 1985.

16 E. C. Bunning, R. Coutinho and G. H. van Brussel, *et al.*, 'Preventing AIDS in drug addicts in Amsterdam', *Lancet*, 1 (1986), 1435.

17 World Health Organisation, *AIDS among Drug Abusers* (Copenhagen, 1987), 190.

18 National Academy of Sciences, Institute of Medicine, *Confronting AIDS: Directions for Public Health, Health Care and Research* (Washington, DC, 1986).

19 R. Sullivan, 'Official favors a test program to curb AIDS', *NYT*, 30 May 1986.

20 *Ibid.*

21 *Ibid.*

22 A. Moss, quoted in R. F. Hummel, W. R. Leavy and M. Rampolla, *et al.* (eds.), *AIDS: Impact on Public Policy* (New York, 1986), 56–7.

23 R. Sullivan, 'Addicts' AIDS deaths may be higher than reported, official says', *NYT*, 26 Mar. 1987.

24 F. X. Clines, 'Via addicts' needles, AIDS spreads in Edinburgh', *NYT*, 4 Jan. 1987. See also G. V. Stimson, L. Alldritt and K. Dolan, *et al.*, 'Syringe-exchange schemes in England and Scotland: evaluating a new service for drug users', in Aggleton, Hart and Davies (eds.), *AIDS: Social Representations.*

25 'Some nations giving addicts clean needles', *NYT*, 9 Mar. 1987.

26 'AIDS, sex and needles' (edit.), *NYT*, 29 Mar. 1987.

27 R. Sullivan, 'New York State rejects plan to give drug users needles', *NYT*, 17 May 1987.

28 R. Sullivan, 'Citing "state of emergency", New York starts drug-clinic program to fight AIDS', *NYT*, 12 June 1987.

29 S. R. Friedman, W. M. de Jong, D. C. Des Jarlais, 'Problems and dynamics of organizing intravenous drug users for AIDS prevention', *Health Education Research*, 3 (1986), 49–59.

30 B. Lambert, 'Drug group to offer free needles to combat AIDS in New York City', *NYT*, 8 Jan. 1988.

31 *Ibid.*

32 *Ibid.*

33 B. Lambert, 'Reaction to needles-for-addicts plan', *NYT*, 9 Jan. 1988.

34 'U.S. homes to get a booklet on AIDS', *NYT*, 28 Jan. 1988.

35 J. Schmalz, 'Addicts to get needles in plan to curb AIDS', *NYT*, 30 Jan. 1988. Plans are also described in 'AIDS and drug abuse: no quick fix', *Science*, 239 (12 Feb. 1988), 717–19.

36 P. Kerr, 'Weighing of two perils leads to needles-for-addicts plan', *NYT*, 1 Feb. 1988.

37 'Fighting AIDS and addiction: a start' (edit.), *NYT*, 18 Feb. 1988.

38 H. Evans and M. Santangelo, 'O'C blasts addict plan', *NY Daily News*, 1 Feb. 1988.

39 P. Kerr, 'Experts find fault in new AIDS plan', *NYT*, 7 Feb. 1988. See L. S. Brown and B. J. Primm, 'Intravenous drug abuse and AIDS in minorities', *AIDS and Public Policy Journal*, 3 (1988), 5–15.

40 T. Morgan, 'Inside a "shooting gallery": new front in the AIDS war', *NYT*, 4 Feb. 1988.

41 S. R. Friedman, D. C. Des Jarlais and J. L. Southeran, 'AIDS health education for intravenous drug users', *Health Education Quarterly*, 13 (1986), 383–93. On the cultural significance of needle sharing, see D. C. Des Jarlais, S. R. Friedman and D. Strug, 'AIDS and needle-sharing within the intravenous drug use subculture', in

D. A. Feldman and T. M. Johnson (eds.), *The Social Dimensions of AIDS: Method and Theory* (New York, 1986).

42 S. R. Friedman, D. C. Des Jarlais, J. L. Southeran, *et al.*, 'The AIDS epidemic among blacks and Hispanics', *Milbank Quarterly*, 65 (suppl. 2) (1986), 455–99.

43 D. C. Des Jarlais, S. R. Friedman and W. Hopkins, 'Risk reduction for the acquired immunodeficiency syndrome among intravenous drug users', *Annals of Internal Medicine*, 103 (1985), 755–9, at 758.

44 *Ibid.*

45 B. Lambert, 'Needles for addicts: test phase begins', *NYT*, 26 June 1988.

46 *Ibid.*

47 B. Lambert, 'Study supports New York's needle plan', *NYT*, 6 June 1988. Also E. C. Buning, G. H. A. van Brussel and V. van Santen, *et al.*, 'Amsterdam's drug policy and its implications for controlling needle sharing', in R. J. Battjes and R. W. Pickens (eds.), *Needle Sharing among Intravenous Drug Users: National and International Perspectives*, NIDA Research Monograph No. 80 (Washington, DC, 1989). Battjes and Pickens concluded that 'Preliminary evaluation of the Amsterdam program suggests that the program has been successful in reducing needle sharing among IV drug abusers, and it has not resulted in increased drug use among program participants', p. 181.

48 P. W. Brickner, R. A. Torres, M. Barnes, *et al.*, 'Recommendations for control and prevention of human immunodeficiency virus (HIV) infection in intravenous drug users', *Annals of Internal Medicine*, 110 (1989), 833–7; G. Mulleady, P. Roderick, S. Burnyeat, *et al.*, 'HIV and drug abuse: essential factors in providing a syringe exchange scheme', *Proceedings of the IV International Conference on AIDS* (Stockholm, 1988) (Abstract 8519); D. Flanagan, S. Burnyeat, B. Wade, H. Clarice, and R. Marten, 'Evaluation of a syringe exchange scheme', *Proceedings of the IV International Conference on AIDS* (Stockholm, 1988) (Abstract 8519); P. Espinoza, I. Bouchard, P. Ballian and J. Polo Devoto, 'Has the open sale of syringes modified the syringe exchange habits of drug addicts?', *Proceedings of the IV International Conference on AIDS* (Stockholm, 1988) (Abstract 8522); G. J. Hart, A. Carvell, A. M. Johnson, C. Feinmann, N. Woodward and A. W. Adler, 'Needle exchange in central London', *Proceedings of the IV International Conference on AIDS* (Stockholm, 1988) (Abstract 8512); D. Goldberg, H. Watson, F. Stuart, M. Miller, L. Gruer and E. Follett, 'Pharmacy supply of needles and syringes – the effect on HIV in intravenous drug users', *Proceedings of the IV International Conference on AIDS* (Stockholm, 1988) (Abstract 8521); and J. S. Wolk, A. Wodak, J. J. Guinan, *et al.*, 'HIV prevalence in syringes of intravenous drug users using syringe exchanges in Sydney, Australia', *Proceedings of the IV International Conference on AIDS* (Stockholm, 1988) (Abstract 8504).

49 H. W. Feldman and P. Biernacki, 'The ethnography of needle sharing among IV drug users and implications for public policies and intervention strategies', in Battjes and Pickens (eds.), *Needle Sharing*. They commented: 'Nor do we have the luxury of awaiting controlled experiments before developing public policies and intervention strategies' (38).

50 L. K. Altman, 'Spread of AIDS virus found slowing among drug users in 3 cities', *NYT*, 16 June 1988.

51 Kerr, 'Weighing of two perils'.

52 J. A. Newmeyer, 'Why bleach? Development of a strategy to combat HIV contagion among San Francisco IV drug users', in Battjes and Pickens (eds.), *Needle Sharing*.

53 J. Blatherwick, 'How to "sell" a needle exchange program', *Canadian Journal of Public Health*, 80 (suppl. 1) (1989), S26–S27.

54 Kerr, 'Weighing of two perils'.

55 N. A. Lewis, 'P.S. 33 fights needle test next door', *NYT*, 2 Nov. 1988.

56 *Ibid.*

57 D. C. Des Jarlais (interview), 2 Aug. 1991.

58 L. K. Altman, 'Needle program is a small one to test concept', *NYT*, 8 Nov. 1988.

59 New York City Department of Health, *The Pilot Needle Exchange Study in New York City: A Bridge to Treatment. A Report on the First Ten Months of Operation* (New York, Dec. 1989).

60 *Ibid.*

61 D. C. Des Jarlais (interview), 2 Aug. 1991.

62 New York City Department of Health, *The Pilot Needle Exchange Study*.

63 Altman, 'Needle program is a small one'.

64 E. Quimby and S. R. Friedman, 'Dynamics of black mobilization against AIDS in New York City', *Social Problems*, 36 (1989), 403–13.

65 B. Lambert, 'The free needle program is under way and under fire', *NYT*, 13 Nov. 1988.

66 E. Williams, quoted in 'Council calls for end to free needles plan', *NYT*, 7 Dec. 1988.

67 B. Lambert, 'New York alters needle plan for addicts to combat AIDS', *NYT*, 13 Nov. 1988.

68 *Ibid.*

69 *Ibid.*

70 M. Marriott, 'Needle plan fails to attract addicts, so it's revised', *NYT*, 30 Jan. 1989.

71 J. Gross, 'Needle exchange for addicts wins foothold against AIDS in Tacoma', *NYT*, 23 Jan. 1989.

72 'Deadly reach of needle proves difficult to block', *NYT*, 8 Feb. 1989.

73 B. Lambert, 'New York's confusing war on AIDS', *NYT*, 19 Feb. 1989.

74 W. E. Leary, 'U.S. needs data on drug and sex habits to halt AIDS, study says', *NYT*, 9 Feb. 1989. See C. F. Turner, H. G. Miller and L. E. Moses (eds.), *AIDS: Sexual Behavior and Intravenous Drug Use* (Washington, DC, 1989).

75 L. W. Sullivan, quoted in 'Sullivan backs needle trading to fight AIDS', *NYT*, 9 Mar. 1989.

76 M. Tolchin, 'Health chief seeks better care for poor', *NYT*, 10 Mar. 1989.

77 M. Tolchin, '2 Bush aides at odds on giving needles to addicts', *NYT*, 11 Mar. 1989.

78 *Ibid.*

79 C. Gardett, quoted in 'U.S. sending mixed signals on trade-ins of dirty needles', *NYT*, 15 Mar. 1989.

80 K. J. Cooper, 'Officials laud free needle programs', *Philadelphia Inquirer*, 25 Apr. 1989.

81 *Ibid.*

82 New York City Department of Health, *The Pilot Needle Exchange Study*.

83 M. Marriott, 'Drug needle exchange is gaining but still under fire', *NYT*, 7 June 1989.

84 B. Weinraub, 'President offers strategy for U.S. on drug control', *NYT*, 6 Sept. 1989; M. Marriott, 'Doubts greet drug plan in New York', *NYT*, 7 Sept. 1989.
85 A. H. Malcolm, 'In making drug strategy, no accord on treatment', *NYT*, 19 Nov. 1989.
86 M. Marriott, 'Addicts awaiting treatment often face delays and panic', *NYT*, 10 Jan. 1990.
87 T. S. Purdom, 'Dinkins appoints advisors on drugs and top positions', *NYT*, 24 Jan. 1990.
88 T. S. Purdom, 'Dinkins to end needle plan for drug users', *NYT*, 14 Feb. 1990.
89 *Ibid.*
90 B. Lambert, 'Myers opposes needle project to curb AIDS', *NYT*, 10 Apr. 1990.
91 *Ibid.*
92 *Ibid.*
93 B. Lambert, 'Health chief is criticized on AIDS shift', *NYT*, 10 May 1990.
94 *Ibid.*
95 G. Kolata, 'Black group attacks using bleach to slow spread of AIDS', *NYT*, 17 June 1990.
96 *Ibid.*
97 K. Johnson, 'New Haven plans to give drug addicts new needles', *NYT*, 24 May 1990.
98 *Ibid.* Also, 'New Haven needle project gets 20 addicts on first day', *NYT*, 15 Nov. 1990.
99 D. M. Fox, 'AIDS and the American health polity: the history and prospects of a crisis of authority', in E. Fee and D. M. Fox (eds.), *AIDS: The Burdens of History* (Berkeley, 1988).
100 J. C. Rossman and S. D. Pomrinse, 'New York City', in L. H. W. Paine (ed.), *Health Care in Big Cities* (New York, 1978); and P. S. Arno and R. G. Hughes, 'Local policy responses to the AIDS epidemic: New York and San Francisco', *New York State Journal of Medicine*, 87 (1987), 264–72.
101 Fox, Day and Klein, 'Power of professionalism', 104.
102 R. Porter, 'Epidemic of fear', *New Society*, 4 Mar. 1988, 24–5.
103 Quimby and Friedman, 'Dynamics and black mobilization'.
104 New York City Department of Health, *The Needle Exchange Pilot Study*.
105 S. C. Joseph to D. Axelrod (letter), 27 Dec. 1989.
106 D. C. Des Jarlais (interview), 5 Aug. 1991.
107 C. Levine, 'Has AIDS changed human subjects research?', *Law, Medicine and Health Care*, 16 (1988), 167–73.
108 At the time of writing there are officially sanctioned needle exchanges in New Haven, Conn.; Hawaii; Portland, Oreg.; Seattle, Wash.; and Boulder, Colo. Unauthorised exchanges operate in many other US cities, including New York. See Gay Wachman, 'Our druggies' (letter), *The Nation*, 15 Apr. 1991.

9

Context for a new disease: aspects of biomedical research policy in the United States before AIDS

VICTORIA A. HARDEN and DENNIS RODRIGUES

In the decade since AIDS was recognised in the United States, extraordinary public debate has surrounded the response of the medical establishment, especially the biomedical research enterprise, to the disease. Particular facets of this response have been considered by a number of authors. Gerald M. Oppenheimer, for example, has analysed factors involved in the epidemiological identification of AIDS at the Centers for Disease Control (CDC), and Daniel M. Fox has included biomedical research policy in his identification of a wider 'crisis of authority' in the United States health polity.[1] Lacking, however, has been an interpretation of the capacities, policies, opportunities and restraints that governed how and to what extent federal research organisations could respond to AIDS.[2]

Although such a full-scale evaluation is far too large for a single paper, we will examine two major policy issues and present two case studies that illuminate the context in which the emerging problem of AIDS was integrated into the existing framework of biomedical research sponsored by the National Institutes of Health (NIH).[3] The two policy issues are the structure of the NIH system for distributing grants and the emergence of targeted disease programmes and planning. The NIH grants system had been constructed carefully over three decades and, when confronted with the AIDS challenge, we will argue, functioned with adequate flexibility within its historic edifice. The agency's implementation of targeted research programmes and planning efforts provided an administrative context in which knowledge used to understand AIDS had been created and through which an AIDS research strategy was initially formulated.

The two case studies concern the formulation of guidelines for research on recombinant DNA and the 1976 epidemic of Legionnaires' disease. The former illuminates political concerns during the 1970s about the direction and control of science and, we believe, undergirded the agency's mandate to seek public advice in structuring AIDS advisory boards. The latter, which examines the roles of the

NIH and the CDC in response to another new disease, provides data for comparison with AIDS.

Research funding and NIH grants system

Although precedents for government patronage of medical research extend back to the late nineteenth century, the present system of federal support emerged after the Second World War, fuelled by wartime medical achievements, especially the development of antibiotics.[4] It was necessarily predicated on the assumption that practical results would soon follow the investment of public money, because creation of such a programme required that Americans suspend a deeply ingrained suspicion of government patronage for special groups.[5] Historically, Congress had preferred to support practical scientific endeavours over open-ended basic research, even when a lack of basic knowledge regarding the ventures undertaken resulted in wasted time, effort and money.[6]

The NIH grants system was modelled on the process for allocating scientific funds during the Second World War. Known as the 'peer review' system, its goal was to fund research on the basis of merit and of priorities determined by the granting agency. University-based investigators submitted research proposals, which were separated by the NIH according to subject area and referred to groups of non-federal scientists who were experts in each area – i.e. the peers of the proposers. After receiving ratings on their scientific merit from the review panels, the applications were reviewed a second time by the advisory councils for each institute. These bodies were comprised of physicians, scientists and laypersons, who considered the proposals from the perspective of each institute's mission, placing them in the context of nation-wide policy concerns about diseases and of the need for further research in selected areas. From the time an investigator submitted a proposal until the time funds were received, about eight or nine months elapsed, under normal circumstances. Grant monies were channelled to the principal investigators through the institutions with which they were affiliated.[7]

Studies of the peer review system began almost immediately after it was established. By 1976, some twenty-two studies had been conducted by congressional committees, by both Republican and Democratic administrations, by the scientific community and by NIH itself. Major issues discussed in these deliberations included conflict of interest, inability to provide adequate review in highly specialised areas, concern that the review groups were not representative of the current trends in science, fear of missing the unrecognised genius by funding only 'safe science', the volume of grants assigned to study section members and the burden for both applicants and reviewers imposed by new laws and regulations.[8] In the years just before AIDS was identified, the studies continued. Concerns about fairness, for example, surfaced in a 1977 appropriation hearing. A congressman queried NIH director Donald S. Fredrickson about allegations that the system was 'really an old boys' club' and that there was no 'provision for appeals'. Fredrickson noted that another committee had conducted yet another intensive review of the system and produced recommendations for establishing an appeals system and for reducing even further the possibility of cronyism or conflict of interest in awarding grants.[9]

Also of major concern in the late 1970s was the impact of economic forces on research funds awarded under the system. One measure of this was the increase in 'indirect costs' to support research. Indirect costs were defined as compensation to institutions for overhead expenses incurred in housing federally sponsored research. Heating and cooling, additional laboratory space and added maintenance costs fell into this category. The total cost of any grant represented the sum of direct and indirect costs. In 1947, when the first funds were awarded, indirect costs had been set at 8% of the direct costs of research. In 1955 Congress raised the indirect cost rate to 15% and by 1963, the rate had risen only to 16%.[10] Beginning with the oil crisis in 1974, however, indirect costs began to spiral upward, and by 1979 they had risen to 26.7%. The sharp increase in energy costs was the factor cited most frequently by recipient institutions as responsible for the increase. By the end of the 1970s, inflation had so increased the total cost of funding research that fewer grants could be supported. If the percentage of indirect costs for 1979 had been the same as the 1966 rate, for example, an additional $228 million would have been available in 1979 for research projects.[11]

During the years before AIDS was identified, the NIH grants system had become an elaborate, much-studied process designed to identify and support meritorious research through the judicious expenditure of taxpayer dollars. NIH and university administrators, Congress and biomedical scientists were most concerned with the impact of inflation on grants and with questions of accountability, fairness and scientific merit. Within this larger framework, as will be discussed below, the agency projected lines of research in annual plans and attempted to guide the course of research toward those health problems with which large segments of the public were concerned.

Managing the research enterprise: planning initiatives and targeted research

A second policy objective during the decade before AIDS was the refinement of existing policies to ensure progress in biomedicine toward specifically defined goals. In part, it was expressed through initiatives for planning programmes and for targeted research efforts. Both emerged after the grants programme had already functioned for more than a decade, and they represented a slight philosophical shift in management of the enterprise, which had been based on two major premises: (1) that biomedical science would advance best by allowing individual scientists to propose lines of research and to follow up serendipitous observations, and (2) that a substantial investment in basic laboratory research was the method most efficient in the long term for producing practical clinical applications.[12] By the 1970s, however, these concepts had been modified after extensive study by Congress and outside groups.

Reliance on individual initiative to guide research came into question in 1965 when a blue ribbon panel appointed by President Lyndon B. Johnson stipulated that one of the most important organisational needs of NIH was 'strengthening of its capacity for long-term planning'. The next year a congressional committee investigation of the Department of Health, Education and Welfare (DHEW) pointedly noted 'the lack of effective planning procedures' as the 'most glaring deficiency' observed.[13] These studies did not negate the importance of the individual initiative concept but rather reflected the growing size and complexity of the research enterprise. Furthermore, they coincided with the introduction by the Johnson administration of a new budgeting system, called Planning–Programming–Budgeting (PPB), which sought to integrate agency planning and budgeting for greater administrative control and efficiency.[14] In response, the NIH elevated the Office of Program Planning within the administration and instructed it to place emphasis on working with individual institutes in developing long-range plans.[15]

A decade later the Assistant Secretary for Health launched another planning initiative, articulated in the 1974 publication, *Forward Plan for Health.* In this document the DHEW detailed activities to be supported by all of its agencies, including the NIH, for the fiscal years 1976–80. By 1977 individual agencies published their own annual planning documents separately. At the NIH, two major goals of the process were to identify research that spanned categorical institute lines and thereby promote co-ordination of effort and to integrate the planning process with both the budget and the legislative processes during each year. This integrated approach produced plans that included as many different scientific opportunities as possible.[16]

Closely allied with the concept of planning for research was an increasing emphasis on targeting specific diseases for intensified research. This initiative challenged the premise that free-ranging scientific inquiry into fundamental biological questions was the most direct route to clinical applications. By the waning years of the Johnson administration, the President and research lobbyists were calling for results from the investment in a quarter-century of basic research. Noting in 1966, for example, that 'a great deal of basic research has been done', Johnson stated that 'the time has come to zero in on the targets by trying to get our knowledge fully applied'.[17] This trend was continued and escalated during the administration of Richard Nixon with enactment of the

National Cancer Act that launched a 'War on Cancer' and with subsequent initiatives against heart disease and stroke.[18] Between 1971 and 1975, in fact, Congress passed seventeen public laws directing NIH to emphasise research on particular areas, including sickle-cell anaemia, Cooley's anaemia, multiple sclerosis, sudden infant death syndrome, diabetes, arthritis, Huntington's disease and epilepsy.[19]

Although research on specific diseases was to be emphasised in these programmes, considerable leeway existed in deciding how best to attack each malady. Much targeted money was utilised in projects that had broad implications, such as studies of a possible link between cancer and viruses, research on the immune system and improved techniques in molecular biology. In the decade before AIDS was identified, NIH research plans noted the high priority given to studies in these basic fields.[20] Funds designated for cancer research, for example, were utilised in support of immunology and virology, fields that had proved fruitful in the 1970s and had implications for many different diseases. In 1977 the National Cancer Institute (NCI) provided 48% of the total NIH investment in immunology and 69% of NIH support in virology.[21]

The planning and targeted research efforts reflected Congress's concern with assuring steady progress toward defined goals. Both of these initiatives arose outside the NIH, and implementation strategies reflect the agency's efforts to comply with congressional mandates. Neither introduced radical restructuring within the NIH; indeed, both had the effect of refining policies and procedures toward what Congress perceived as a more effective implementation of the agency's mission. The plans sought to identify and foster promising areas of research that might otherwise be missed and to minimise duplication of effort. Targeted research programmes raised the visibility of particular diseases with which substantial segments of the public were concerned. In concert with the modifications in the grants process, these management imperatives reveal the NIH in the pre-AIDS era as a mature institution, whose policies and procedures were directed at fine-tuning a broadly accepted and widely supported mission.

Policy making on the frontiers of science: recombinant DNA

In addition to responding to broad areas of policy concern in the 1970s, NIH addressed a number of issues concerning the ethics of science. These included investigation of fraud and misconduct in research, the ethics of research on human subjects and regulation of recombinant DNA research. The last provides an excellent case study for examining the emergence of new scientific techniques and the politics of biomedicine in the years preceding AIDS.

In 1974, a group of eminent scientists called attention to the potential hazards of newly discovered recombinant DNA techniques.[22] Their announcement sparked debates over control of this powerful new biological tool. These occurred within a social climate sceptical of science. Discoveries in the 1960s about toxic side effects of antibiotics, the environmental dangers of chemical pesticides, carcinogens in food and the ethical dilemmas posed by manipulation of individuals in behavioural research had produced misgivings about the value and humanity of modern science and technology.[23]

In response to both scientific and lay concerns, the Secretary of the Department of Health, Education and Welfare chartered a Recombinant DNA Advisory Committee (RAC), headed by the director of intramural research at NIH and comprised of scientists and laypersons.[24] In February 1975 an international conference of molecular biologists convened at the Asilomar conference centre in California. Participants reached consensus about the appropriate levels of laboratory safeguards for experiments of differing potential risks and about the types of experiments that would be prohibited voluntarily until knowledge increased about the hazards or safety of the technology. Working from these findings, the RAC drafted guidelines that were promulgated in 1976.[25]

Some environmental activists complained that, in formulating the guidelines, the RAC had been dominated by 'technocratic' interests focused on safety alone to the exclusion of democratic debate on the ethics of recombinant experiments. A number of bills were introduced into Congress to legislate regulations for the research, but none was enacted. As the 1970s drew to a close, the highly vocal debate subsided, experience having demonstrated that biological disaster was unlikely. During the early 1980s, the controls were loosened, but the RAC was retained as a standing committee to evaluate research that broke new ground in recombinant DNA research.[26]

This case study illustrates several characteristics of federal biomedical research policy during the later 1970s. First, NIH leadership was expected by the larger biomedical community in dealing with such issues. Since recombinant DNA technology cut across disciplinary and geographic lines, no single professional scientific society could claim leadership, nor could any single institution. Second, the agency was implicitly charged by the scientific community with making the case for voluntary guidelines to Congress and thereby heading off legislative regulations that most scientists believed would be detrimental to research. Finally, in assuming leadership of the recombinant DNA discussions, the NIH had to respond to lay concerns about the potential social consequences of scientific decisions. The political benefits gleaned from lay participation in the RAC reinforced the wisdom of existing NIH practice to include lay members on major advisory committees.

Research and public health crises: Legionnaires' disease

The formulation of recombinant DNA guidelines raised broad questions about leadership and regulation in science. A second case study, focusing on the 1976

Table 1. *NIH and CDC initial expenditures on AIDS and Legionnaires' disease (dollars in thousands)*

AIDS							
	Fiscal year						
	82	83	84	85	86	87	88
CDC	2,050	6,202	13,750	33,298	62,152	136,007	304,942
NIH	3,355	21,668	44,121	63,737	134,667	260,907	430,570
Legionnaires' disease							
	Fiscal year						
	76	77	78	79	80	81	82
CDC	162	1,533	1,931	2,047	1,521	1,647	1,115
NIH	—	—	—	622	1,266	1,635	1,027

Sources: Office of Financial Management, CDC; NIH Data Book 1990, US Dept. of Health and Human Services, Public Health Service, NIH.

outbreak of Legionnaires' disease, provides insight into the functioning of well-established federal protocols. It also provides perspective on the respective roles of the CDC and the NIH in addressing an extraordinary public health problem in the pre-AIDS period.[27]

As many authors have detailed, in 1976 at an American Legion convention in Philadelphia, Pennsylvania, a mysterious respiratory malady struck 182 Legionnaires or members of their families. Twenty-nine of them died. The microbial cause of this epidemic eluded identification for some months, during which questions were raised about the ability of biomedicine to respond to unknown pathogens. Eventually, however, CDC microbiologists identified a gram-negative bacterium as the etiological agent. This organism, *Legionella pneumophilia*, had long been known to microbiologists. What had been unknown was its affinity for growing in modern air handling systems, which distributed the pathogen through the air to unwary victims. Subsequent studies of stored sera revealed that this organism also had been the cause of previous unsolved respiratory epidemics.[28]

Research on Legionnaires' disease was initially conducted by the CDC and, after October 1979, also by the NIH. As the first line of defence against epidemic outbreaks, the CDC launched an epidemiological investigation and utilised standard laboratory methodology in searching for the etiological agent. Once *Legionella pneumophilia* had been identified, the agency researched the biology, immunology and pathogenic microbiology of the organism. It also instituted serologic and pneumonic surveillance and investigated rapid diagnostic techniques. Research sponsored by the NIH fell into four categories:

clarification of the etiologic niche, elucidation of the mode of transmission, delineation of the pathology through the development of animal models and characterisation of different stains and surface antigens in order to develop diagnostic tests and possible vaccines.[29]

Legionnaires' disease was reminiscent of classic epidemics in that it struck rapidly, with considerable mortality, then waned just as rapidly. As the figures in Table 1 show, research expenditures by the CDC rose rapidly, peaked and then levelled off as the disease was understood. Those by NIH started later, and rose to a level comparable with those of CDC. Within a year, Legionnaires' disease had reaffirmed the belief that infectious disease problems were understood and controllable within the existing medical and scientific paradigm. The very success, moreover, of the CDC in identifying the cause of Legionnaires' disease and in developing diagnostic and preventive methods against it may have strengthened the expectation that other new diseases, including AIDS, would be quickly resolved through existing techniques.

Placing the NIH response to AIDS in context

This brief examination of the two issues and two case studies offers some insight to the historical context in which the NIH responded to AIDS. Broadly speaking, the NIH mission in the post-Second World War era had been defined by Congress as research, especially on chronic diseases, for which few or no medical interventions were effective. Steady progress toward specific goals, accountability and fairness in awarding grants were issues of primary concern. The advent of AIDS brought stress to the carefully built biomedical research system when political advocates suggested that it should have been structured to permit a more rapid response to the deadly new disease.

AIDS came as a surprise to the medical community. It was not just an outbreak of a well-known pathogen or even a new organism within a well-understood family of pathogens. Since no previous transmissible agent had been known that killed by undermining the immune system, research aimed at understanding such an agent had not previously been conducted, nor had it been contemplated in structuring plans for future research. In this sense, the research planning process was useless. By proposing support for lines of research in fruitful areas, however, such as molecular immunology and retrovirology, the planning process had fostered the new production of knowledge that proved useful in understanding the new disease. The 1981 NIH research plan, for example, which was prepared during the spring of 1981, before publications about AIDS had appeared, highlighted as promising areas new immunologic techniques, such as recombinant DNA technology and hybridoma cell fusion, and studies on interferon and other biological response modifiers – all fields that were utilised in research on AIDS.[30]

Once AIDS was identified, moreover, it was rapidly incorporated in the planning process as a promising area for research support. The plan written in 1982 contained two items of note with regard to AIDS. In the National Institute of Allergy and Infectious Diseases section, the institute proposed to redirect some funds during fiscal year 1983 (which began in October 1982) for new initiatives 'in response to unusual or emerging new opportunities, including acquired and inherited immunologic disorders'. Since AIDS was the only known 'acquired' immunologic disorder, this notation reflects the institute's interest in the new disease. Similarly, in the NCI section, 'Kaposi's sarcoma in homosexual men and concurrent viral infections' was specified as one area to be emphasised. These comments not only reveal institute awareness of AIDS as a research problem but also underscore the difficulty of formulating focused research programmes in the absence of knowledge about the etiological agent.[31]

Perhaps the single issue most assailed by critics of the NIH response to AIDS was the length of time between identification of a new disease threat and the receipt of the first grant dollars by university researchers who wished to investigate it. In *AIDS in the Mind of America*, for example, Dennis Altman asserted: 'There were two major problems in funding AIDS research, the first being the question of how much money would be available, the second involving the very cumbersome process whereby that money was made available to researchers.'[32] As we have seen, however, the question of whether the grants system could or should be a vehicle for rapid distribution of funds in response to public health emergencies had not been considered in studies of the process.[33] Given the history of the system and its many modifications, it could be compared to a vast ship laboriously constructed over many years. Critics who complained that the system did not distribute funds rapidly were denouncing the ship because it could not fly.[34]

Further, the impact of indirect costs had taken a severe toll on the number of new grants that could be awarded and on the percentage of approved grants, both new and continuing, that could be funded. During the time that AIDS emerged, the NIH leadership struggled to maintain a minimum number of new awards that would be funded each year in order to prevent further erosion in the number of investigators pursuing federally sponsored research.[35] The constrained situation, which was exacerbated by the budget-cutting policies of Ronald Reagan's administration, compromised the agency's flexibility to initiate new activities, including research on AIDS. Operating in a 'zero sum game' meant that, in the absence of new appropriations, substantial amounts of research support for new initiatives could be generated only by reducing or eliminating existing programmes or by transferring funds from one agency to another.[36]

In August 1982, just over one year after the first paper identifying AIDS had appeared, the NCI issued its first request for investigators to submit grant applications relating specifically to AIDS.[37] This formal request was designed to bring into AIDS work those institutions that did not already participate in an NCI co-operative agreement, a funding mechanism similar to a grant, but one in which the awarding institute retained substantial programmatic involvement. Institutions already involved in co-operative agreements were eligible to apply for supplemental funds to inaugurate research on AIDS.[38] In addition, individual scientists could submit proposals relating to AIDS through the normal grants process, and recipients of grants whose work could be redirected towards AIDS were permitted to alter their projects if their home institutions agreed.[39] In April 1982 Bruce Chabner, director of NCI's Division of Cancer Treatment noted this flexibility in his testimony before California Representative Henry Waxman's Subcommittee on Health and the Environment during the first congressional hearing on AIDS: 'It is hard to account for the amount of money that they [NIH grantees] have invested through redirection of their grant support, but we feel it is considerable in view of the number of publications that have appeared.'[40]

Within the NIH intramural programme, flexibility to redirect research was considerably greater.[41] The first AIDS patient was treated in the NIH Clinical Center in June 1981, the same month that the initial publication about AIDS appeared.[42] During the ensuing year, a group of physicians and scientists redirected some or all of their research to explore the unusual disease and treat additional patients. One of them described the process: 'When we first started studying AIDS, just by word of mouth, there were a lot of people who wanted to look at various aspects [of the disease] . . . Very quickly we got a group of people . . . who didn't need an organized program because they all had a common interest.'[43] Another recalled that no one initially dropped existing projects to work on AIDS, 'they simply worked longer', into the evenings and on weekends.[44] In 1982 Robert C. Gallo, chief of the Laboratory of Tumor Cell Biology in the NCI, redirected his laboratory's research toward searching for the etiological agent after hearing evidence presented by James Curran, chief of the CDC's venereal disease branch, that AIDS was transmitted via blood and compromised the function of T-lymphocytes, white blood cells that were key components of the immune system. Curran's presentation suggested to Gallo that AIDS might be caused by an agent closely related to the retroviruses on which his laboratory was already working.[45]

These experiences of researchers in the intramural NIH programme reveals the existence of an informal network of investigators – inside and outside of government – in which information about AIDS was shared actively. In addition, internal correspondence files attest to official co-ordination and liaison efforts between agencies of the Public Health Service (PHS) within the Department of Health and Human Services (DHHS). In a memorandum dated 31 July 1981, for example, William H. Foege, director of the CDC, requested NCI co-operation in studying the 'outbreak' of Kaposi's sarcoma. Specifically, Foege asked that NCI augment the CDC's epidemiologic studies with therapy trials and with 'studies designed to define possible microbiologic, immunologic, and/or toxic roles in oncogenesis'. Vincent T. DeVita, Jr, director of NCI, referred the memo to Bruce Chabner, then acting director of NCI's Division of Cancer Treatment, asking Chabner to arrange for 'someone to join in'. Chabner responded by organising a national conference in September 1981 aimed at developing a 'coordinated strategy regarding the etiology and treatment of Kaposi's sarcoma'. In January 1982 Edward N. Brandt, Jr, the Assistant Secretary for Health in DHHS, officially requested 'greater participation' in AIDS investigation by NCI, the National Institute of Allergy and Infectious Diseases and the National Institute on Drug Abuse to supplement epidemiologic work by the CDC. The directors of each institute reported on activities underway, and on 3 March the CDC hosted a conference on AIDS for PHS scientists. Further liaison activities continued, including the formation in July 1982 of an NIH 'working group' that co-ordinated efforts among institutes and provided agency representation on AIDS matters.[46]

The 1970s emphasis on targeted research made AIDS a candidate for earmarked funds as soon as it was established that the disease was no ordinary epidemic outbreak that would be quickly controlled. Expenditures on AIDS rose dramatically during the first three years after the disease was identified, and continued their exponential climb for years thereafter. The only parallel to this striking growth in funds for a single disease was the sharp rise in cancer funds after enactment of the 1971 National Cancer Act. Comparing funding patterns for AIDS and Legionnaires' disease underscores the magnitude of the difference. Figure 1 compares the overall pattern of research funding for Legionnaires' and AIDS during the years after each was first identified. Although some authors have suggested that public and political sentiment compelled a larger research effort for Legionnaires' disease, our analysis shows that spending on AIDS outstripped Legionnaires' research in overall magnitude and in acceleration of spending over time. Furthermore, NIH funding for Legionnaires' began only after the etiologic agent was identified. In the case of AIDS, however, NIH provided more funds for research than did the CDC within the first full fiscal year after the disease was recognised – two years before a retrovirus was accepted as the etiological agent. The differences in funding patterns for these diseases reflect early recognition of the differences between the diseases themselves. Legionnaires' disease proved to be a transient and limited disease event in sharp contrast to AIDS' relentless exponential growth.

The experience of developing guidelines for recombinant DNA research also had an impact on NIH's AIDS policy. Although there were important differences between recombinant DNA and AIDS – the former, though worrying, posed a hypothetical problem while the latter involved actual death and suffering – both confronted the biomedical community with critical issues relating to the

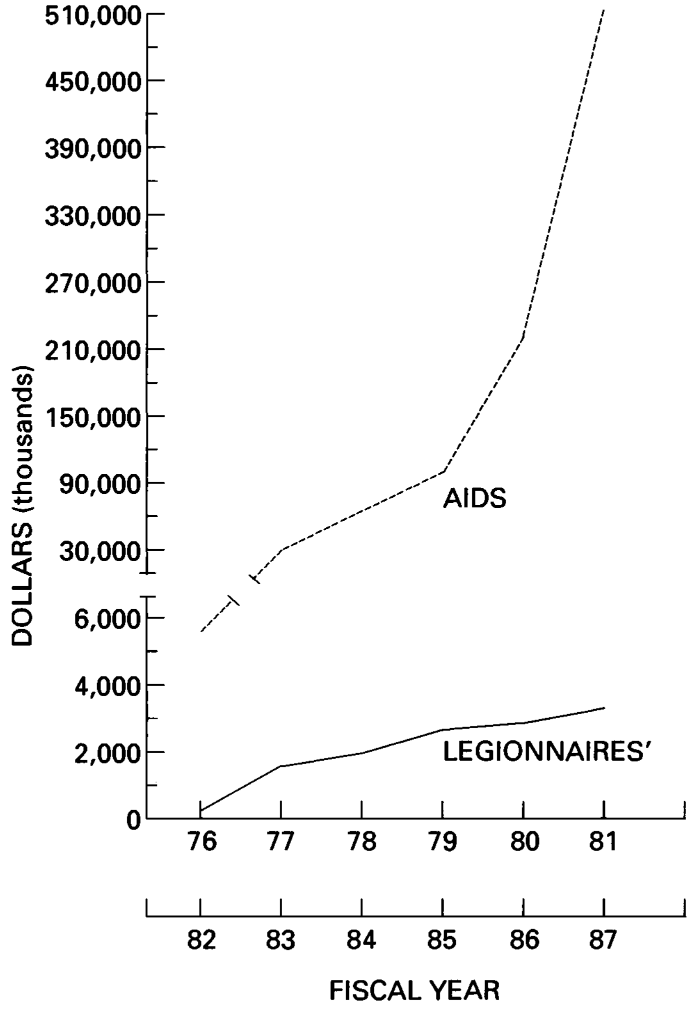

Figure 1 Initial PHS funding for AIDS and Legionnaires' disease

Sources: Office of Financial Management, CDC; NIH Data Book 1990, US Dept. of Health and Human Services, Public Health Service, NIH.

public health and welfare. The emergence of guidelines governing recombinant DNA research followed recognition of a theoretical but discernible risk. Response to AIDS was similar, once the magnitude of the risk had been ascertained. In 1980 and 1981, however, as unusual cases of what came to be known as AIDS were discussed between medical experts, the magnitude of the risk was not apparent. When epidemiological evidence mounted that it was a communicable disease with identifiable risk factors and that it was recognised in other countries as well as in the United States, both medical and lay communities mobilised to combat it.

Although it is impossible to pinpoint an exact moment when the enormity of this new disease became apparent, the evolution of phrases describing AIDS provides some clues. During the summer and autumn of 1981, the terms 'epidemic' – usually placed within quotation marks – and 'outbreak' were often used, sometimes in association with phrases such as 'dramatic increase'. By early 1982, the phrases 'accident of nature' or 'experiment of nature' appeared, indicating recognition of a problem that was larger than a limited 'outbreak'. During the next few months, however, the terminology escalated as appreciation increased about the scope of the disease and its lethal nature. In April 1982, Bruce Chabner of the NCI testified that AIDS was a 'new, complex, and very serious illness', which had become 'a public health problem of great magnitude'. At the same hearing, James Curran of the CDC suggested that known cases might be 'merely the tip of the iceberg', and that although the entire range of manifestations of the disease remained unclear, they were 'quite disturbing'. By mid-1982, epidemiological evidence had convinced many investigators that AIDS was caused not by an environmental agent but rather by an infectious pathogen, probably transmitted by blood as well as by sexual activity. This finding may well represent the turning point in medical understanding of AIDS because of its ominous implications. An environmentally caused disease might be limited geographically and/or controlled with existing public health methods, while an unknown, communicable pathogen would be much more difficult to identify, prevent and cure. Reflecting this realisation in his rhetoric, one investigator returning from a scientific meeting on AIDS in July 1982 strongly stressed the need for 'a most urgent response'.[47]

Internal NIH administrative structures for addressing AIDS also emerged parallel with funding increases as the scope of the disease became better understood. The NCI, concerned with the incidence of Kaposi's sarcoma, organised an informal 'working group' relating to AIDS in March 1982, four months before the agency-level group was established.[48] By 1985 all the NIH working groups had been consolidated and elevated into the NIH AIDS executive committee, and in 1987, the Secretary of the Department of Health and Human Services, chartered the AIDS Program Advisory Committee (APAC), with four of the thirteen appointed members designated as 'members of the general public'.[49] To strengthen internal co-ordination further, an NIH Office of AIDS Research was created the following year.[50] The careful attention by NIH to lay involvement in the APAC was doubtless reinforced by the recent experience of constituting the RAC, as well as by earlier precedents of lay representation on advisory councils. Conversely, the demands of AIDS activists to participate in such official bodies reflected their assumption that power should be shared in making some medical decisions, an attitude that was in part an outgrowth of the experience with recombinant DNA.

In a 1989 article, historian Charles Rosenberg described social reaction to an epidemic as occurring in a predictable pattern like the acts in a drama.[51] In act three pressure is generated for decisive and visible community response. In the past, such ritualist actions have included quarantines and religious fasting or prayer. Large congressional allocations for research and the establishment of visible bureaucratic structures may be seen as a similar response in our secular, scientifically oriented society. Viewed in this light, much of the stridency directed against the federal biomedical research enterprise had its origin in the need to propel such an appropriate community response. The few issues addressed in this paper, however, suggest that considerable flexibility existed in the federal biomedical research response to AIDS even before external criticism appeared. They also indicate that careful attention to historic medical, scientific and organisational forces is indeed necessary to understand how the biomedical research community formulated and implemented its response to the deadly disease.

NOTES

1 Gerald M. Oppenheimer, 'In the eye of the storm: the epidemiological construction of AIDS', in Elizabeth Fee and Daniel M. Fox (eds.), *AIDS: The Burdens of History* (Berkeley, 1988), 267–300; Daniel M. Fox, 'AIDS and the American health polity: the history and prospects of a crisis of authority', in Ronald Bayer, Daniel M. Fox and David P. Willis (eds.), 'AIDS: the public context of an epidemic', special issue, *Milbank Quarterly*, 64 (suppl. 1) (1986), 7–33; reprinted in Fee and Fox (eds.), *AIDS: The Burdens of History*, 316–43. See also Stephen P. Strickland, *Research and the Health of Americans: Improving the Policy Process* (Lexington, Mass., 1978).

2 'Introduction', in Bayer, Fox and Willis (eds.), 'AIDS: the public context of an epidemic', 3.

3 The NIH is the research arm of the Public Health Service in the US Department of Health and Human Services. This department was created in 1980 out of the health and welfare programmes of the former Department of Health, Education and Welfare.

4 The two precedents for federal support of medical research by non-federal scientists were the grants given for research on yellow fever by the National Board of Health between 1879 and 1883 and those given for research on venereal diseases by the

Interdepartmental Social Hygiene Board between 1918 and 1921. See Peter Bruton, 'The National Board of Health', PhD dissertation, University of Maryland, 1974; Wyndham D. Miles, 'A history of the National Board of Health, 1879–1893', 2 vols., manuscript, National Library of Medicine, 1970. Within its own laboratories, first called the Hygienic Laboratory and later renamed the National Institute of Health, the US Public Health Service and its predecessor agencies had sponsored research since 1887. See Victoria A. Harden, *Inventing the NIH: Federal Biomedical Research Policy, 1887–1937* (Baltimore, 1986). Standard references on the emergence of the post-Second World War NIH include James A. Shannon, 'The advancement of medical research: a twenty-year view of the role of the National Institutes of Health', *Journal of Medical Education*, 42 (1967), 97–108; Elizabeth Brenner Drew, 'The health syndicate: Washington's noble conspirators', *Atlantic Monthly*, 220 (December 1967), 75–82; Stephen P. Strickland, *Politics, Science, and Dread Disease: A Short History of U.S. Medical Research Policy* (Cambridge, Mass., 1972); G. Burroughs Mider, 'The federal impact on biomedical research', in John Z. Bowers and Elizabeth F. Purcell (eds.), *Advances in American Medicine: Essays at the Bicentennial*, 2 vols. (New York, 1976), II, 806–71; Donald S. Fredrickson, 'The National Institutes of Health yesterday, today, and tomorrow', *Public Health Reports*, 93 (1978), 642–7; Daniel M. Fox, 'The politics of the NIH extramural program, 1937–1950', *Journal of the History of Medicine and Allied Sciences*, 42 (1987), 447–66; Stephen P. Strickland, *The Story of the NIH Grants Program* (Lanham, Md., 1989).

5 Alvin M. Weinberg, 'In defense of science', *Studium Generale*, 23 (1970), 797–807; reprinted in *Science*, 169 (1970), 141–5. On republicanism and suspicion of patronage for any special group, see Daniel T. Rodgers,'Republicanism: the career of a concept', *Journal of American History* 79 (1992), 11–38.

6 One of the earliest examples of this is found in efforts to survey and map the US coast. See A. Hunter Dupree, *Science in the Federal Government: A History of Policies and Activities* (Cambridge, Mass., 1957; reprint Baltimore, 1986), 29–33. Dupree also noted that in the nineteenth century, Congress created most scientific agencies through the appropriations process in order that they could be controlled – and, if necessary, terminated – by the simple act of withholding funding. Indeed, the organic legislation authorising the existence of the federal laboratory that became the National Institutes of Health was buried in a 1901 sundry civil appropriations act. See *ibid.*, 214–15; Harden, *Inventing the NIH*, 17.

7 Catherine Henley, 'Peer review of research grant applications at the National Institutes of Health 1: the assignment and referral processes', *Federation Proceedings*, 36 (1977), 2066–8; *idem*, 'Peer review of research grant applications at the National Institutes of Health 2: review by an initial review group', *ibid.*, 2186–90; *idem*, 'Peer review of research grant applications at the National Institutes of Health 3: review by an advisory board council', *ibid.*, 2335–8. On political questions relating to the peer review system, see Don K. Price, 'Endless frontier or bureaucratic morass?', *Daedalus*, 107 (Spring 1978), 75–92.

8 Major studies of the NIH peer review system are summarised in 'Selected studies, investigations, and recommendations related to the National Institutes of Health: an annotated bibliography', in Appendix D, 'Selected staff papers', of US President's Biomedical Research Panel, *Report of the President's Biomedical Research Panel*,

30 April 1976, 4 appendices, 4 suppl. (Washington, DC, DHEW Publication Nos. (OS) 76–500 through 76–509, 1976), 1–32.

9 US Congress, House Committee on Appropriations, *Departments of Labor and Health, Education and Welfare Appropriations for 1978: Hearings before a Subcommittee of the Committee on Appropriations*, part 3, 'National Institutes of Health' (Washington, DC, 1977), 56–7.

10 The rate set in 1963 was 20% of 'allowable' direct costs, which, because of the accounting methods used, resulted in a net rate of about 16% of total direct costs. See Kenneth T. Brown, 'Indirect costs of federally supported research', *Science*, 212 (1981), 411–18.

11 Brown, 'Indirect costs of federally supported research'; *Report by the Comptroller General of the U.S.: Indirect Costs of Health Research. How They are Computed, What Actions are Needed* (Washington, DC, General Accounting Office Publication No. HRD–79–67, 1979), esp. 9–10; Saunders MacLane, 'Total reporting for scientific work', *Science*, 210 (1980), 158–63. Because indirect cost rates were negotiated with individual institutions and because accounting practices in calculating direct and indirect costs varied among institutions, these figures represent overall trends.

12 These concepts have been discussed in most historical studies of the NIH grants programme. See, for example, *The Nation's Medical Research*, vol. 5 of US President's Scientific Research Board, *Science and Public Policy: A Report to the President*, by John R. Steelman, 5 vols. (Washington, DC, 1947), esp. 9, 27; Strickland, *Politics, Science, and Dread Disease*, 174; Shannon, 'The advancement of medical research', 105.

13 US President's NIH Study Committee, *Biomedical Science and its Administration. A Study of the National Institutes of Health*, Report to the President (Washington, DC, 1965), 1; US Congress, House Committee on Interstate and Foreign Commerce, *Investigation of HEW*, Report of the Special Subcommittee on Investigation of the Department of Health, Education and Welfare, 89th Cong., 2nd sess., 13 October 1966, House Rept. No. 2266 (Washington, DC, 1966), 110.

14 There is a large literature on this programme. Two review papers with useful citations are W. Ken Fisher, Jr, 'PPBS in proper perspective', *Federal Accountant*, 21 (1972), 22–32; B. H. DeWoolfson, 'Federal PPB: A ten year perspective', *ibid.*, 24 (1975), 52–61. In 1971 strict adherence to PPB format was abandoned as a requirement for submission of agency budgets, although many agencies continued to utilise its planning and programme analysis features.

15 The NIH did not implement the recommendation of the President's NIH Study Committee (known as the Wooldridge Committee after its chairman, physicist Dean E. Wooldridge) that a policy and planning council be formed to assist the NIH director in formulating programmes. The NIH position was explained in 'The initial NIH commentary, biomedical science and its administration, the Wooldridge Committee Report', staff paper, April 1965, Office of the Director central files, NIH (hereafter cited as OD central files, NIH).

16 US Congress, House Committee on Appropriations, *Departments of Labor and Health, Education, and Welfare Appropriations for 1975: Hearings before a Subcommittee of the Committee on Appropriations*, part 3, 'Department of Health, Education, and Welfare' (Washington, DC, 1974), 2–3; *Forward Plan for Health,*

FY 1976–80 (Washington, DC, 1974); US National Institutes of Health, *Forward Plan, FY 1979–83*, administrative document (Bethesda, 1977), copy in NIH Historical Office.

17 Johnson's remarks to medical and hospital leaders, 15 June 1966, quoted in *Research in the Service of Man: Biomedical Knowledge, Development, and Use*, proceedings of a conference sponsored by the subcommittee on government research (pursuant to S. Res. 218, 89th Cong.) and the Frontiers of Science Foundation of Oklahoma for the Committee on Government Operations, United States Senate, 24–7 October 1966 (Washington, DC, 1967), 5. See also Strickland, *Politics, Science, and Dread Disease*, chapters 9–10.

18 R. A. Rettig, *Cancer Crusade: The Story of the National Cancer Act of 1971* (Princeton, 1977); Natalie Davis Spingarn, *Heartbeat: The Politics of Health Research* (Washington, DC, 1976).

19 The specific initiatives with citations and appropriation amounts are listed in 'Congressional initiatives in biomedical and behavioral research', in Appendix D of *Report of the President's Biomedical Research Panel*, 36–8, 40.

20 See, for example, US National Institutes of Health, *Draft Research Plan, FY 1981–1983*, administrative document (Bethesda, 1979), copy in NIH Historical Office, 35–6.

21 *Ibid.*, 65. NCI also supported Robert C. Gallo's research in retrovirology during the 1970s. In 1979 Gallo announced his discovery of the first human retrovirus. See Robert Gallo, *Virus Hunting: AIDS, Cancer and the Human Retrovirus: A Story of Scientific Discovery* (New York, 1991), 99–115.

22 Stanley N. Cohen, Annie C. Y. Chang, Herbert W. Boyer and Robert B. Helling, 'Construction of biologically functional bacterial plasmids *in vitro*', *Proceedings of the National Academy of Sciences, U.S.A.*, 70 (1973), 3240–4. Paul Berg, David Baltimore, H. W. Boyer, Stanley N. Cohen, R. W. Davis, D. S. Hogness, D. Nathans, R. Roblin, J. D. Watson, S. Weissman and N. D. Zinder, 'Potential biohazards of recombinant DNA molecules', *ibid.*, 71 (1974), 2593–4. On the recombinant DNA controversy, see John Richards, *Recombinant DNA: Science, Ethics, and Politics* (New York, 1978); Nicholas Wade, *The Ultimate Experiment: Man-Made Evolution* (New York, 1977; rev. edn, 1979); David Archer and Stephen P. Stich, *The Recombinant DNA Debate* (Englewood Cliffs, NJ, 1979); Joan Morgan and W. J. Whelan (eds.), *Recombinant DNA and Genetic Experimentation* (New York, 1979); Sheldon Krimsky, *Genetic Alchemy: The Social History of the Recombinant DNA Controversy* (Cambridge, Mass., 1982). Initial research on recombinant DNA was supported by grants from the National Institute of Child Health and Human Development and the National Institute of General Medical Sciences.

23 On the anti-science movement, see Herbert Marcuse, 'The individual in the great society', in B. M. Gross (ed.), *A Great Society* (New York, 1968); Jacques Ellul, *The Technological Society* (New York, 1964); Theodor Roszak, *The Making of a Counter Culture* (New York, 1969); *idem*, *Where the Wasteland Ends* (Berkeley, 1972); Don K. Price, 'Purists and politicians', *Science*, 163 (1969), 25–31; Philip M. Boffey, 'AAAS convention: radicals harass the establishment', *Science*, 171 (1971), 47–9; Philip Handler, 'The federal government and the scientific community', *Science*, 171 (1971), 144–51; Harvey Brooks, 'Can science survive in the modern age?', *Science*, 174 (1971), 21–30.

24 Initially the committee was comprised primarily of experts on recombinant DNA technology, with few lay members, but, over the ensuing years, its composition changed to include a greater proportion of non-scientists.

25 Donald W. Fredrickson, 'Values and the advance of medical science', in *Integrity in Institutions: Humane Environments for Teaching, Inquiry, and Healing*, proceedings of a conference sponsored by the Association of Academic Health Centers, at the University of Texas Health Science Center, Houston, Texas, 25 May 1989 (in press), 18–23; quotation from 20. See also *idem*, *Decision of the Director, National Institutes of Health, to Release Guidelines for Research on Recombinant DNA Molecules* (Bethesda, Md., 1976); *idem*, 'A history of the recombinant DNA guidelines in the United States', in Morgan and Wheelan (eds.), *Recombinant DNA and Genetic Experimentation*, 151–60.

26 The guidelines were published in the *Federal Register*, 41, 131 (7 July 1976), part 2, 27902–943, and as National Institutes of Health, *Guidelines for Research Involving Recombinant DNA Molecules* (Bethesda, Md., 1976). For views of scientists on the guidelines, see, for example, Stanley N. Cohen, 'Recombinant DNA: fact and fiction', *Science*, 195 (1977), 654–7; for criticism, see David Dickson, *The New Politics of Science* (Chicago, 1984; 2nd edn, 1988), pp. 243–60; Wade, *Ultimate Experiment*, chapter 11. Principal regulatory bills were sponsored by Senator Edward M. Kennedy and Representative Paul G. Rogers. See Barbara J. Culliton, 'Recombinant DNA bills derailed: Congress still trying to pass a law', *Science*, 199 (1978), 274–7.

27 Before the Second World War, the NIH mission had included responding to epidemics of infectious diseases and monitoring incidence of mortality and morbidity. In the post-war era, as the federal health bureaucracy expanded, these responsibilities were assumed by the newly created Centers for Disease Control, whose initials, CDC, originally stood for Communicable Disease Center. See Elizabeth Etheridge, *Sentinel for Health: A History of the Centers for Disease Control* (Berkeley, 1992); Fitzhugh Mullan, *Plagues and Politics: The Story of the United States Public Health Service* (New York, 1989), 128–65.

28 Gary L. Lattimer and Richard A. Ormsbee, *Legionnaires' Disease* (New York, 1981), 1–8, quotation from 1. On the history of this epidemic, see also Gordon Thomas and Max Morgan-Witts, *Trauma: The Search for the Cause of Legionnaires' Disease* (London, 1981); *idem*, *Anatomy of an Epidemic* (Garden City, NY, 1982); Paul Clinton, comp., *Legionnaires' Disease: A Bibliography* (London, 1989). For an evaluation of the biomedical response to the epidemic, see also Barbara J. Culliton, 'Legion fever: postmortem on an investigation that failed', *Science*, 194 (1976), 1025–7; *idem*, 'Legion fever: "failed" investigation may be successful after all', *Science*, 195 (1977), 469–70.

29 Information on funding was supplied by the Financial Management Offices, CDC and NIH. Information on areas of NIH research, which included both intramural and extramural projects, was supplied by the Research Documentation Section, Information Systems Branch, Division of Research Grants, NIH.

30 US National Institutes of Health, *Draft Research Plan, FY 1984*, administrative document (Bethesda, 1982), copy in NIH Historical Office.

31 *Ibid.*, 66, 116.

32 Dennis Altman, *AIDS in the Mind of America* (Garden City, NY, 1986), 48.

33 The only report in which we have found concern about the speed of the process was a General Accounting Office study of grants made by the National Cancer Institute, which complained about 'significant delays' in the funding process. See US General Accounting Office, Comptroller General of the United States, *Administration of Contracts and Grants for Cancer Research, National Institutes of Health, Department of Health, Education, and Welfare B-164031(2)* (Washington, DC, 1971), 2–3. The National Cancer Act of 1971 (and later the National Heart, Blood Vessel, Lung, and Blood Act) authorised those institutes to award grants up to $35,000 without review by the institute advisory councils. These small grants, however, were not exempted, as the General Accounting Office report had recommended, from peer review by scientific panels.

34 In 1983 Representative Theodore S. Weiss of New York utilised the ship metaphor in a slightly different argument. He stated that 'persuading NIH to pay greater attention to the AIDS epidemic is like rerouting a luxury liner that takes ten miles to turn'. See US *Congressional Record*, House, 3 May 1983, 2587.

35 Donald S. Fredrickson, 'Communal resources, community responsibilities', *Clinical Research*, 29 (1981), 239–47.

36 Donald S. Fredrickson, 'Biomedical research in the 1980s', *New England Journal of Medicine*, 304 (1981), 509–17.

37 National Cancer Institute, 'Request for cooperative agreement applications: RFA NIH-NCI-DCT-CTRP-82-13. Studies of AIDS (Kaposi's sarcoma and opportunistic infections)', *NIH Guide for Grants and Contracts*, 11, 9 (13 August 1982), 3–7.

38 William D. DeWys to Michael A. Friedman, 18 November 1981, file 'Kaposi's sarcoma', Division of Cancer Treatment, National Cancer Institute, Bethesda, Maryland (hereafter cited as DCT, NCI).

39 US Public Health Service, *Grants Policy Statement* (Washington, DC, DHEW Publication No. (OS) 77–50,000 (Rev.), 1 October 1976), 36. Grantees must discuss changes in the scope of their research with their home institution, which receives and distributes NIH grant funds. This provision in grants policy provides one of the essential differences between the grant and the contract instruments for funding research.

40 US Congress, House Committee on Energy and Commerce, Subcommittee on Health and Environment, *Kaposi's Sarcoma and Related Opportunistic Infections: Hearing before the Subcommittee on Health and the Environment of the Committee on Energy and Commerce*, 97th Cong., 2nd sess., 13 April 1982 (Washington, DC: Government Printing Office (Serial No. 97–125), 1982), 32. In preparing for the testimony, Chabner's office had identified twenty-seven existing grants and contracts 'with some applicability to the subject' of Kaposi's sarcoma and estimated that $433,000 of the 1981 funding for these projects might be utilised in studying the new disease. See 'National Cancer Institute, Kaposi's sarcoma', table with attachments, 6 Apr. 1982, file 'Kaposi's sarcoma', DCT, NCI.

41 Intramural investigators do not have to apply for grant funds to support their research. Their work is reviewed by their administrative superiors and, periodically, by each institute's board of scientific counsellors, comprised of non-federal scientists who are experts in fields supported by the institute. Within this structure

and within the limitations of budgets, intramural scientists can redirect their research at any time if they believe a new direction is more promising.

42 Victoria A. Harden and Dennis Rodrigues, interview with Thomas Waldmann, 14 March 1990, Bethesda, Maryland, copy in NIH Historical Office. Dr Waldmann was the admitting physician for this patient.

43 Victoria A. Harden and Dennis Rodrigues, interview with Henry Masur, 22 November 1989, Bethesda, Maryland, copy in NIH Historical Office.

44 Victoria A. Harden and Dennis Rodrigues, interview with Robert B. Nussenblatt, 25 April 1990, Bethesda, Maryland, copy in NIH Historical Office.

45 Gallo, *Virus Hunting*, 134–5. Gallo's account of his decision to investigate AIDS is representative of the approach taken by many scientists. Most investigators, whether on the staff of the intramural programme on the Bethesda campus or supported by grants at universities, were committed to particular research projects on a long-term basis. Seeing the research through to its conclusion and publishing experimental findings were prerequisites for continued funding and for status among scientific peers. A serendipitous finding could lead research projects in new directions, but most investigators were wary of jumping from topic to topic. A decision to redirect research towards AIDS was usually made only after it became clear that a laboratory's existing expertise could be utilised to illuminate some aspect of the disease. See comments on this in Alan N. Schechter, 'Basic research related to AIDS', in Victoria A. Harden and Guenter B. Risse (eds.), *AIDS and the Historian: Proceedings of a Conference at the National Institutes of Health 20–21 March 1989* (Washington, DC, NIH Publication No. 91–1584, 1991), 45–50.

46 William H. Foege to Vincent T. DeVita, Jr, memorandum re 'Kaposi's sarcoma and opportunistic infections', 30 July 1981; DeVita to Bruce Chabner, n.d., handwritten note on same memorandum; Chabner to Foege, memorandum re 'Kaposi's sarcoma conference', 6 August 1981; Vincent T. DeVita, Jr, to Edward N. Brandt, Jr, memorandum re 'Current work on Kaposi's sarcoma', 18 February 1982; William H. Foege to Bruce A. Chabner, 23 February 1982, all in file 'Kaposi's sarcoma', DCT, NCI; Edward N. Brandt, Jr, to Vincent DeVita, Richard Krause and William Pollin, memorandum re 'Kaposi's sarcoma', 7 January 1982; Richard M. Krause to Edward N. Brandt, Jr, 15 January 1982; James B. Wyngaarden to BID Directors, memorandum re 'Working group on epidemic of acquired immunosuppression, opportunistic infections, and Kaposi's sarcoma', 13 July 1982, all in file 'Kaposi's sarcoma, January 1982', Intramural Research 5–15, OD central files, NIH.

47 The words 'epidemic' and 'outbreak' are found in numerous early documents; Chabner and Curran testimony from the April 1982 hearing on *Kaposi's Sarcoma and Related Opportunistic Infections* (see n. 40), 34, 10; Arthur S. Levine to Vincent T. DeVita, Jr, memorandum re 'Update on the epidemic of acquired immunodeficiency sarcoma-opportunistic infection', 2 July 1982, file 'Kaposi's sarcoma, July 1982', Intramural Research 5–15, OD central files, NIH.

48 Associate Director for Field Studies and Statistics, DCCP, NCI to William Blattner, Mark Greene, James Goedert, Robert Biggar, Dean Mann, Robert Hoover and Deborah Winn, memorandum re 'Epidemiology working group on Kaposi [*sic*] sarcoma', 8 March 1982, file 'Intramural research 5–15, March 1982', OD central files, NIH.

49 Documentation of the creation of the NIH AIDS executive committee is in Director, NIH to Acting Assistant Secretary for Health, memorandum re 'NIH coordination of AIDS research', 15 October 1985, file 'Intramural research 5–15, October 1985', OD central files, NIH. On creation of the APAC, see Otis R. Bowen, 'Formal determination', 21 August 1987; 'Charter, acquired immunodeficiency syndrome program advisory committee', 21 August 1987; and 'Amendment to the charter of the acquired immunodeficiency syndrome program advisory committee', 23 November 1987, copies in files of the NIH Office of AIDS Research.

50 Statutory authorisation for the NIH Office of AIDS Research is in the Omnibus Health Bill, PL 100–607, 4 November 1988, US *Statutes at Large*, vol. 102, 3076.

51 Charles E. Rosenberg, 'What is an epidemic? AIDS in historical perspective', in 'Living with AIDS', special issue, *Daedalus*, 118 (Spring 1989), 1–17.

10

The NHS responds to HIV/AIDS

EWAN FERLIE

Introduction[1]

The unexpected and sudden emergence of the HIV/AIDS epidemic in Britain in the 1980s – as in other countries – posed difficult issues for individuals, pressure groups and social movements, health care organisations, and the national political and policy process alike. This experience has to be captured quickly if memories are not to erode and while accounts are beginning to emerge of the governmental and ministerial process,[2] of the formation of policy 'communities' and lobbies acting on formal policy making;[3] and the role of professional experts[4] in influencing the formation of national policy, there is still work to be done on the response by District Health Authorities which represent the operational tier of the National Health Service (NHS) although we can build on an earlier analysis of a single case in a high prevalence locality.[5] Some American work has examined the organisational response in particular localities[6] suggesting interesting local sources of variation. But we need to know more about how British health care organisations responded to an unanticipated epidemic – and new epidemics have been rare in First World health care systems – which has had such important societal consequences.

HIV can be seen as a single health care issue but one which was processed within a particular organisational form (District Health Authorities (DHAs)) which span a multiplicity of issues, involve a wide variety of interest groups, contain a strong political component and also a range of powerful professional groups. Some political theorists have questioned the ability of any single issue to retain profile within such political settings,[7] so the politics of neglect may characterise the handling of the HIV issue – particularly in its later stages – as much as the politics of attention. The two hundred or so District Health Authorities were created as fully independent authorities only in 1982, but all have their own personalities, and (as we shall see) central guidance often exerts only a limited influence on what is decided in particular localities. Decision making is often diffuse in as much as a variety of internal interest groups lobby and form coalitions, but often external influence is weaker, especially in teaching Districts where clinicians and clinical academics exert most power. The power structure is best described as one of 'bounded pluralism'. From April 1991 the role of the DHA began to undergo major changes as White Paper reforms providing for a 'managed market' were progressively introduced and the split between the new purchaser and provider roles started to intensify.

Between 1982 and 1991, therefore, the District Health Authority (and its affiliated Units) represented the key operational tier of the NHS responding to the HIV issue, yet we know little about the nature of this response. DHAs were of course themselves changing and restructuring in the 1980s as the pull of the new Thatcherite political economy became evident, most notably with the introduction of general management in 1984/5. By the end of the decade, the general managerial cadre was – at least in some localities and some issues – able to act as a countervailing force against the professional blocs. The HIV/AIDS issue can also be used as a tracer to explore more general theories of innovation in health care organisations. HIV/AIDS may force the question of change: effective organisational and managerial responses to such a complex and uncertain issue might be thought to be very different from the incrementalist or steady state responses which have previously characterised health care management.[8]

The methodology used is one of longitudinal, comparative, case studies, stretching back now for almost a decade but often with more distant pre-histories (such as the prior response to hepatitis B in the locality) to consider as well. The knowledge base for such longitudinal case study work draws both on contemporary history and the sociology of organisations, and thus both has to develop a history which is interpretive as well as chronological, and which can present a plurality of accounts from different viewpoints, and a sociology which is empirically grounded, inductive and sensitive to the impact of time, rather than concerned to build high level theory. Initial analysis has concentrated on individual case studies,[9] but there is now the opportunity to move on to comparative case study work, where patterns may begin to emerge in the data.

The first section of the paper therefore reviews some of the broader literature which will be considered. The second section describes in more detail the methodology and the data base, while in the third section some patterns across the case studies are considered. The fourth section explores questions of role creation and organisational design, and the paper concludes by summarising the analytic themes identified and speculating about possible developments in the 1990s.

Some organisational and managerial aspects to the HIV/AIDS epidemic

In this section some organisational and managerial literature is reviewed in order to identify a perspective with which to interrogate the case study material.

The problem of strategic service change in the NHS

The problem of ensuring rapid change in complex health care systems is of course a general one, but one which applies with particular force to the conditions of urgency created by the emergence of a new epidemic. The wider literature on organisational change in the NHS highlights the obstacles of effecting strategic change and the frequency of implementation failure so that policies which are agreed in principle are often not put into practice.[10] Often health care systems have been seen as exhibiting 'institutional paralysis', so that any coalition for change is likely to be insufficiently powerful to reconfigure services and will be unable to switch resources away from dominant groupings.[11] 'Implementation deficits' within the NHS increasingly emerged as a research and policy problem for the centre in the 1980s, as national policies for change (for example in mental illness services) were not reflected in change at local level. Nowhere were the pressures towards institutional inertia more acute than in dense metropolitan settings such as Inner London (which is precisely where HIV/AIDS first emerged as an issue) and where managerial agendas were retrenchment led rather than centred on service development.

A further question relates to the leadership of change in such a fragmented system. It is not obvious who are the champions of change, and four potential and alternative bases should be considered. The first scenario is that the push for service development could come from social movements such as gay organisations, either by lobbying and influencing the response of the public statutory sector, or by constructing a lively and vigorous non-statutory sector to which workload might be contracted out.[12]

A second potential basis could be the appointed members on DHAs. While there is a controversy about the extent to which such members who are formally expected to perform a policy making role in the localities in effect act as no more than 'rubber stamps', some writers argue that they can exert an influence either through setting boundaries and local rules of the game[13] or more proactively, especially through proposals coming from a small but influential subgroup of member 'strategists'.[14]

A third potential basis of leadership could be general management. Indeed part of the Thatcherite political economy of health care has consisted of the attempt to create a clearer managerial focus for driving through change. However, the agendas of the new cadre of general managers appointed in 1984/5 in practice seem to have revolved around financial control, rather than managing strategic service change or organisational development, both of which represent possible alternative constructions of their early brief.[15]

Fourthly, clinicians might emerge as 'product champions' of service innovation, which is a concept which has been used both in studies of industrial innovation[16] and health care innovation.[17] Some of the personal characteristics of the effective product champion have been outlined as follows: a risk taker; a willingness to use all informal as well as formal channels to promote the cause; drive and energy (perhaps to the point of obsessionality).[18] But the social role and the power position of the product champion was also found to be of importance. There may be an interesting further distinction between a 'product champion' whose enthusiasm may be needed to get an idea off the ground and an 'organisational champion' who will be able to work the wider organisation diplomatically.[19] The whole product championing literature draws attention to the importance of people within organisations, and the need for an internal push from particular individuals if rapid service development is to take place.

The role of crisis: its construction, management and aftermath

The naive view that 'necessity is the mother of invention' and that high caseload would force the HIV/AIDS issue up agendas is not confirmed by a comparison of the response in New York and San Francisco, where HIV/AIDS attracted less governmental attention in New York despite (at least initially) a higher caseload.[20] The balance of local political and organisational forces and the way in which issues are received into pre-existing networks may then be important mediating factors, but the degree to which the new issue is accorded 'crisis' status may also play a crucial role.

The theme of crisis management has traditionally provided a rich seam for organisation theorists to mine and the managerial processing of strategic issues may be different in crisis and non-crisis situations.[21] Certainly between 1983 and late 1986–7, HIV/AIDS quickly emerged nationally in the UK as a high profile health issue to a point where it was often labelled as a 'crisis': the early epidemiology was taken as indicating that the UK was only four or so years behind America; an unparalleled national health education programme was launched; and there was high media interest. The HIV/AIDS issue acquired many of the characteristics of a crisis as used by Dutton (importance, immediacy and uncertainty): indeed, it was often said that there had been nothing like it in health care since the Second World War.

Here was a crisis which contained both real and constructed elements but, as predicted, maintenance of the HIV issue on a national policy agenda was to prove more problematic than creation.[22] Issue succession took place and by 1989 the focus of attention had moved on to the health care White Paper. Some have even suggested that the natural history of public policy issues is from crisis to complacency.[23]

How might the perception of HIV as a potential crisis affect the response from health care organisations? Much of the existing literature on organisational crisis[24] stresses the pathological consequences for organisations of the emergence of crisis-as-threat: increased centralisation and formalisation, with a breakdown in integrating structures; the erosion of information channels; the exiting of key human resources; a loss of trust and loyalty as a low commitment organisation emerges; the emergence of groupthink and scapegoating at a small group level. Crisis is here seen as making the creativity and flexibility needed even less likely to occur.

There is, however, a less considered counter scenario of crisis-as-opportunity.[25] Major change can only take place when the perception of a crisis forces an awkward issue up crowded agendas. The construction of crisis-as-opportunity by a band of early learners may lead to very different patterns of behaviour from that envisaged in the earlier model: continuing pressure from pioneers; the formation of special groups who reach out to the rest of the organisation; high energy and commitment levels; strong integration and cohesion within the newly emergent group. Even in this more optimistic scenario, however, there remains the problem of how to manage the post-crisis aftermath perhaps as disillusion or burn out sets in. Tracing through the response by DHAs to the HIV/AIDS issue provides an opportunity to develop some of the literature on the management of crisis within a health care setting.

HIV/AIDS – a naturally occurring opportunity for organisational design and development

The perception that the NHS has remained in many ways a frustratingly under-developed organisation created in some localities an alternative general managerial agenda throughout the service: the creation of greater autonomy and flexibility in organisational design.[26] Certainly this had resonance in the localities: in one of the case study districts, the District General Manager wrote: 'it was recognised from an early stage that one of the key management challenges was not just to implement change, but to develop the organisation's capacity to cope with change. The aim, in a sense, was to create a different kind of organisation, capable of learning, responding to and even generating change, rather than simply reacting to it.'[27] We see here a more global attempt in the 1980s to create a new form of 'learning' NHS which would have a much better developed capacity to change. Such an organisation might look very different from the old highly rule-bound decision making structures and emphasise more fluid forms of decision making, such as task forces or *ad hoc* groups. HIV/AIDS can be used as a tracer issue to assess the extent to which this broader agenda was actually operationalised.

This is because these general arguments for organisational design and development were highly applicable in the rapidly emerging HIV/AIDS issue where there was a requirement for speedy action; strategic planning was taking place under conditions of gross uncertainty; and there was a premium on much better

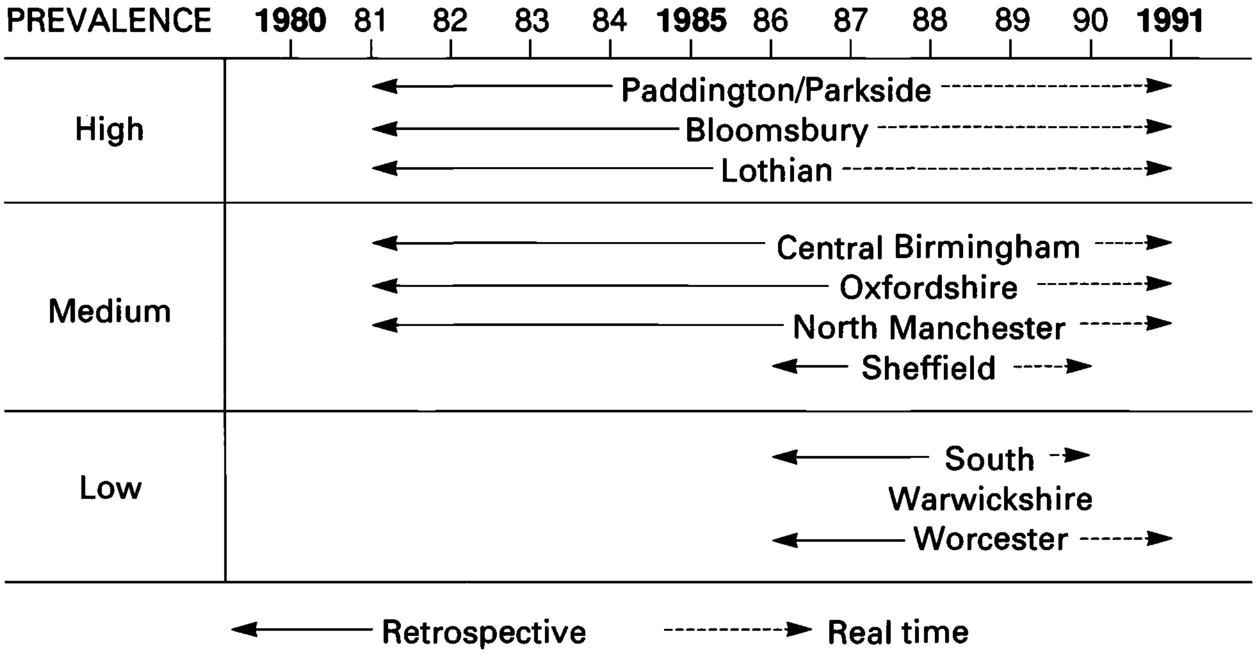

Figure 1 Organisational and managerial responses to AIDS: data base

forms of lateral communication as a host of very different specialties which had historically never had contact found themselves unexpectedly going to the same meetings (for example, sexually transmitted diseases (STDs) and dentistry). Moreover, the emergence of earmarked resources provided a windfall which could be used to accelerate such processes of service development. But while windfall growth can promote the politics of extraordinary change, new interest groups may quickly emerge into a dominant coalition to capture the new resources, excluding constituencies which emerged just that little bit later.[28] This points to the critical importance of very early choices in designing machinery to process the new HIV/AIDS issue and the retaining of control over the new resources.

Case studies and approach

The basic methodology adopted is that of the comparative, longitudinal, case study. Figure 1 describes the nine case studies which are being considered in this analysis.

As the key questions were essentially historical, processual and related to the meanings which actors attributed to their actions, qualitative methodology was indicated. Methods included: interviews with a wide range of stakeholders in each of the systems (forty to fifty per case); attendance at meetings; and examination of archival material (both formal minutes, informal memos and ephemera). Typically an intensive period of analysis (say five months) would be followed up by more limited monitoring over time. By use of these methods the aim is to produce research on organisations which move beyond the ahistorical, aprocessual and acontextual limitations of previous work, but which can engage with micro organisational processes through time.[29]

An interesting methodological question concerns the relationship between the perspectives of history and of organisation theory. While some branches of organisational theory (such as the contingency theoretic approach popular in the 1960s and 1970s) are indeed ahistorical, other methodologies are far more sensitive to the importance of history in shaping organisational power structures, attitudes and assumptions. Sometimes the skills of an historian have not always been apparent within these analyses but there are now some important and interesting exceptions. For example, Chandler's[30] analysis is essentially a business history of the rise of the modern corporation as an institutional form and of management as a social grouping. For contemporary historians the understanding of institutions which so dominate decision making processes in modern societies might also be thought to be important. In the 1980s there has been if anything a growing move within organisation theory towards more processual and historical perspectives (for example Pettigrew's study of strategic change processes in ICI).[31] The life cycle and organisational transitions approaches to the study of organisations indeed explicitly organise themselves around the passage of time.[32]

At the same time sociology continues to influence even those branches of organisation theory which are sympathetic to historically informed analysis. As a result there is a greater emphasis on the building and testing of formal theoretical models than in many purely historical accounts. However, as in many historical accounts (narrative history excluded), the pluralist nature of reality is acknowledged and competing interpretations of the past presented. There are thus areas of overlap and continuity of interest between the disciplines. The potential for a fruitful dialogue between history and organisation theory is now apparent.

The pattern of service development in the 1980s

What observations can be made from reviewing these nine case studies?

Local variation in service development

The first relates to the substantial variation apparent at local level in the development of service strategies: the localities did not mechanistically replicate national guidelines. Although health services are formally organised within a National Health Service designed to promote territorial equity, the higher tiers played an indirect and facilitative role – especially through the provision of financial incentives – and the periphery (especially the big inner city DHAs) retained much of the initiative. Thus neighbouring authorities or even particular hospitals within the same authority exhibited quite different responses.

Most obviously this is because the local epidemiology (and perception of it) varies: the bulk of the caseload has fallen upon perhaps twenty mainly inner city DHAs, while most districts still report very low caseloads. One analysis of different case studies suggests that this metropolitan/regional divide may be crucial, distinguishing between two types of response.[33] The first pattern is metropolitan hospital-based, perhaps professionally dominated with an emphasis on disease prevention through control of infection and laboratory measures such as blood screening. The treatment model was based on open access genito-urinary medicine (GUM) clinics with in patient care in specialist units. The second community-based model was characterised by multi-sectoral networks, involving or even led by the voluntary sector. There was an emphasis on health education. Care was provided where possible in community settings with the emphasis on support groups.

But the present case studies indicate that differences in the pattern of development are even more finely grained than this two-category model. While clinical 'product champions' emerged in all three of the high prevalence districts, they were drawn from very different backgrounds (immunology, infectious diseases, public health) and included clinical academics as well as service clinicians. In addition the nature of the developing service system has clearly been affected by the local environment and by local antecedent conditions. Responses are thus not only issue-based, but are shaped by the wider histories of the host systems into which this new issue is received. Local political cultures were also important: the context was perhaps more receptive in Inner London (where the gay social movement was best developed), while some of the councils in the regional centres showed greater nervousness about dealing with issues related to sexuality, and the Scottish political culture complicated efforts to develop services for drug injectors.

There were some other sources of local variation. Hospitals under long-term threat of closure have sometimes diversified into HIV/AIDS more readily than those whose future was secure. Teaching hospitals offer an important 'supply side' motor of service development, with clinical academics able and anxious to develop research into new diseases. The recent experience of other epidemics (hepatitis B, tuberculosis), or a local infection control tradition represented other examples of how the past could affect patterns of development.[34]

A good example of how antecedent conditions affected responses can be drawn from St Mary's, Paddington, London, which was one of the very first hospitals to respond clinically: not only was there a need in the local population, but the existence of an infection control tradition and facility, the formation of a prior research group around hepatitis B, and the international networks of clinical academics which could be used to access the earlier American experience all helped to provide local clues in advance of the issue being constructed nationally.

Finally, in the face of loose top down guidance localities quickly built up service systems around early product champions and centres of activity. There is organisational process as well as structure. Who emerged in the earliest days to raise consciousness around the issue was found to vary widely across the Districts, and some product champions were much more powerful than others. Under these circumstances, organisational histories soon diverged as virtuous and vicious circles built up. An issue quickly attracts a history, a label and an image, and becomes seen as either a good or a bad service to be associated with.

The dominant role of health care agencies

We can, however, advance some tentative generalisations on the basis of the early case study evidence. The first is that the prime focus at operational level has generally been the District Health Authority (or its Units) – given its control over key resource flows – and that therefore it is here that we should look if we want to understand how the key service development decisions in the localities have been made.

Certainly lobbying from social movements (rapidly organising from 1984/5 within voluntary groups such as the Terrence Higgins Trust) managed to achieve influence at departmental level and at field level, at least in London (especially over non-resource issues such as ward regime and counselling). But their influence wilted in the middle of the hierarchy, and there was little evidence that voluntary groups were integrated into district planning and policy machinery nor was there large-scale contracting out to the voluntary sector. Outside Inner London, the nervousness of some local authority councils on gay issues given restrictive national guidance could force DHAs to choose priorities for the development of links. There were some examples of statutory facilities (such as phonelines) being set up in competition with voluntary provision. Links between HIV/AIDS projects and education departments were also made more difficult by local authority loss of nerve over sex education following new legislation which increased the power of Boards of Governors. This sometimes made it more difficult for special HIV projects to gain access to schools.

Another potential lead at local level were local authority social services departments, but these agencies generally came on stream later than DHAs, reflecting the lag in special national funding mechanisms, and lacked the powerful product champions found in DHAs. In the absence of a specific budget, joint care planning around HIV/AIDS between health and social care agencies often remained at the useful but limited information exchange level, rather than moving on to the formation of joint strategy.

The stance of the higher tiers (Regions and the Department) during the early years of the epidemic can be broadly seen as facilitative, supplying resources which could enable bottom up developments from the Districts to happen given fairly broad policy guidelines. As the HIV issue matured, however, and as flows of resources escalated, this picture began to change. There was also increasing pressure from the centre to monitor the spend by Districts. While the pace of regional development varied (North West Thames was often seen as the 'lead region' on HIV/AIDS), regional 'offices', procedures and strategies were also emerging elsewhere by 1988/9, beginning to place constraints around Districts' freedom of manoeuvre. Regions often adopted policies to 'spread the workload', although implementation was patchy.

Crisis, crisis management and its aftermath

The notion of 'crisis' provides a useful construct which must itself be deconstructed. While every DHA experienced the national 'crisis' constructed around HIV/AIDS in 1986/7, local 'crises' varied in length and intensity, according to perceptions of local caseload and skill in crisis construction. Once the national stimulus had been removed, it could be difficult to keep the HIV/AIDS issue going in low prevalence districts, but in 1986/7 mobilisation of the national crisis could generate funding even in areas of low prevalence. Local perceptions of crisis did not always emerge: in one low prevalence district studied, the early response did not emerge from a 'crisis' at all (cases had not yet emerged), but a gradual process of people becoming aware of HIV/AIDS as an issue, and thereafter reflecting on how it might impact on their professional roles.

Despite this variation in most Districts there was a perception that HIV/AIDS posed urgent, immediate and uncertain issues that amounted to a label of 'crisis'. It is useful to distinguish between the initial, medium-term and long-term effects of organisational crisis. In many Districts, there was evidence of an initial short-term crisis driven by the arrival of patients which was associated with pathological reactions from the organisation. There is a link here to Goffman's (1963) work on stigma, where it is suggested that interactions with stigmatised patients may be characterised by withdrawal and irrational beliefs about the dangers posed by the stigmatised person. Crisis construction and a focus on 'infection' may of course have negative implications for quality of the treatment and care of those already infected.

Local control of infection crises blew up in the early days, often characterised by rumour, staff anxiety and even panic. These were routed to clinical control of infection fora which were largely independent of management. In Paddington, for example, the AIDS/HIV issue was received into the organisation as a control of infection issue.[35]

In the Scottish Board studied, an epidemiological crisis arose when a virologist who was practising using the new HTLV-3 test examined stored bloods from drug users: quite unexpectedly 38% tested positive.[36]

In the medium term experience of local crisis seemed on the whole to have had energising and creative effects in the Districts. An extraordinary outburst of energy, enthusiasm and activity took place as high commitment groups began to emerge. In one medium prevalence regional centre an energetic special team arose as the centrepiece of the DHA's response, linking into a wide variety of DHA and external agencies as 'change agents'.

By 1989, however, it was possible to take a longer term and less rosy view on the aftermath of crisis. Crisis-based structures were clearly vulnerable when early projections had to be revised downwards: had the HIV/AIDS lobby been crying wolf all along? Even services which had developed rapidly now faced a less benign climate.[37] Staff burn out was another problem in these centres of high activity, as exceptionally high activity levels could not always be sustained.[38]

Thus by 1989 it was clear that a number of early innovators were withdrawing from the field as a result of burn out, and that a new generation might be needed for the 1990s. The HIV/AIDS issue still poses questions of how to manage continuing rather than episodic change. While the first wave of the epidemic around gay men in the mid-1980s aroused a high level of energy, this may prove difficult to sustain in the 1990s when there may be a further requirement to develop service systems for drug users and women and children.

From innovation to institutionalisation

A transition from birth and early development on the one hand to maturity and institutionalisation on the other may be particularly difficult for innovative organisations, as the institutionalisation stage involves removing the freedom of manoeuvre, space for entrepreneurial activity and creativity which were welcomed in the organisation's infancy, and which became part of the organisation's self-image and ideology.[39]

Initially innovation had often taken place by delegation down to self-starters who had been selected on the basis of their potential. These innovations were thus developed and managed in a highly unusual fashion.[40]

Yet in a number of districts 1988/9 was seen as a difficult period of transition from these crisis-based early years to a period of 'normalisation', in which the projects which had emerged were to be more closely tied to mainstream machinery. A number of first stage 'innovators' got out of HIV/AIDS and into still newer growth points; staff became increasingly aware of their inability constantly to expand their brief and even started to be labelled as 'veterans'; more managerial capacity arose to complement much of the clinically based early response; and formal 'offices' and structures emerged to place boundaries around action. The transition is essentially a Weberian one from the personal to the impersonal, and from the charismatic to the bureaucratic.[41]

Yet given the need for continuous rather than episodic change, such normalisation and institutionalisation may be premature. HIV services may instead need the ability to cope with continuing change over a much longer timescale. It will be interesting to see how many of the original service developers are driven out by the new more rule bound order.

Strategy formulation and implementation

The development of strategies for HIV/AIDS has severely tested the planning and management capacity of DHAs as responding to such a complex and uncertain issue requires the development of methodologies very different from formal long-range corporate planning. At the very least, uncertainty has to be scripted in rather than scripted out; different scenarios considered; and as much flexibility as possible retained.[42]

Strategy was an important issue for many Districts in their attempt to structure the gross uncertainty which they faced, but there was much variation: some had produced formal documents (which were not always embedded in organisational behaviour); in others the uncodified but purposeful behaviour of small groups represented the real strategy. While there were attempts to create special machinery, the construction of a capacity to think strategically and retain strategic flexibility was more elusive. An unfortunate consequence of the special allocation was a tendency to plan for the annual round, with little 'visioning' of what the future might look like.

Using Mintzberg's[43] framework, strategy can be seen as containing both emergent and purposeful elements and we should not assume that strategy always proceeds in a rational-analytic manner but can also be seen as consistency in a stream of decisions through time. In many cases 'strategy' can bless actions which have already emerged as a retrospective labelling of activity. But there were also decision points (such as the construction of the first bid for resources) where the quality of the forward look could have important long-term consequences for the emergent service system. A good example of purposeful strategy would be the first (Community Medicine-based) bid to come out of Bloomsbury DHA (1985) which could be seen as: well founded in local epidemiological evidence (highlighting the importance of the rational component of strategy); shrewd in its assessment of the need to use the windfall to put a coalition together (the political component); and taking care to be broadly based in its assessment of needs outside the acute sector.

Clearly the development of HIV/AIDS services was clearly influenced by covert as well as overt strategies, as HIV/AIDS represented a well-resourced peg on which other issues could fit. In one District HIV/AIDS was a stalking horse in a much wider debate about how health education projects were to be managed; in another it was a way of developing women's services through a prostitutes' outreach project; in others the unspoken objective – especially for finance – was to tear down the ringfence around the special monies and transfer them to pressured base budgets. Formal documentation alone would give a very partial view of some of these covert processes.

There is some evidence that the most effective strategy making combined top down and bottom up planning. The first attempt by one District to develop a strategy led by Community Medicine initially ran into implementation difficulties, due in part to the lack of ownership of the issue in the operating divisions. The response by the centre was to support the creation of Unit level groups which could supply such ownership, and develop strategy through a dialogue between the centre and the units.

Role creation and organisational design

In the first section, it was suggested that leadership around HIV/AIDS could have been supplied from a number of sources and this section considers how such roles have been constructed. Of course the case studies are disproportionately likely to be drawn from high and medium prevalence teaching districts, which may operate distinctive labour markets.

DHA members played a generally reactive role although a friend on the DHA could prove useful in safeguarding funds. In some cases, 'managing up' to the chairman to ensure political cover for sensitive work emerged as an issue for service developers, but members were unlikely to come along with proactive proposals. Nor was HIV/AIDS generally constructed as a major political issue at DHA level (unlike hospital closure proposals), but retained bipartisan support, so even major bids could go through with little discussion.

Their agenda dominated by questions of financial control, the new general managers were on the whole dull in their response to HIV/AIDS. As one respondent remarked: 'general managers are not turned on by AIDS, but by the tag that attaches to AIDS.' Indeed another respondent was developing a financial model of general managerial behaviour: what was the point beyond which the special financial allocation would have to rise before general managers would start to attend HIV/AIDS meetings? Giving the HIV/AIDS issue to a general manager who lacked a sense of personal ownership was counterproductive, and could lead to a damping down of the whole management process. Nor – on the whole – was there much evidence of conscious utilisation of the HIV/AIDS issue as a containable test bed for a more general organisational development and design brief, perhaps reflecting the lack of interest among action oriented managers in developing theories of managerial action.

There were some important redeeming features and interesting exceptions. Those managers who developed the greatest interest in HIV/AIDS tended either to be drawn from clinical backgrounds (and thus retain an interest in strategic service development) or to have had a prior background in service development processes (for instance in drugs services) or to be strong conceptualisers and lateral thinkers (perhaps these managers are also more likely to be found in teaching Districts), and hence interested in the organisational design implications of HIV/AIDS. Nor should the learning curve along which managers had to move be forgotten, given their lack of international clinical networks which could have fed early knowledge in.[44]

Certainly the case studies illustrated the critical importance of clinical product champions in driving change. In all the case studies enthusiasts emerged who pushed for service development, often in the face of scepticism from elsewhere in the organisation. These champions could be some way down the formal hierarchy (such as health education officers in low prevalence areas), but in each of the three high prevalence districts and in some of the medium prevalence districts, an elite consultant (drawn from different specialties) emerged as an important early focus.

These champions were self-confident in their academic backgrounds, skilled in the black arts of running rings around systems (such as using soft research monies as a way around manpower controls), were able to gain access to national policy making and media channels over the heads of the District, and showed drive and energy over a long period of time in building up services. The achievement of a position of power was crucial, and there were also examples of clinical product champions coming up with ideas for service development (for example in drugs services) which faced severe difficulties in their adoption in part because of the peripheral power base of the champions in the organisation. There were also some interesting differences in the balance placed between interfirm diplomacy on the one hand and zeal on the other, and the degree to which HIV/AIDS confirmed a long-standing interest in the world of policy or whether it represented a transforming experience in which champions left the relative shelter of the laboratory for the world of policy and politics. The emergence of active product champions can then have dysfunctional as well as functional consequences for the organisation, as their highly individualistic approaches can pose wider integrating problems. Initially these product champions emerged organically but there have been attempts to create a new cadre in the appointment of a new generation of GUM consultants to develop services in their Districts. It will be interesting to see whether they will in the future emerge as powerful and effective champions of change.

Some of the most effective clinical product champions did not operate in isolation, but were embedded in a wider institutional setting, able to call on the support of Young Turks (such as Senior Registrars) who could undertake much of the planning or service development work, in effect helping to write the first rules for that District. Highly motivated and energetic, they were already senior enough to have won some autonomy, and were making fundamental long-run career choices, but in the end fitted into the world of formal health care organisations.

A little remarked upon consequence of the escalating financial allocations has been the creation of a specialist and largely unregulated HIV labour market, with a growing number of workers employed on very different conditions of service by different authorities, but often on junior grades and on short-term contracts. These posts pulled in younger, mission driven and countercultural workers from social movements who sometimes faced a difficult period of acculturation to the NHS.[45]

Where the acute sector had developed an interest in HIV/AIDS, such workers had only a peripheral impact. Where, however, prevention was more of a priority and such workers were organised into cohesive and energetic teams (perhaps utilising empowerment ideology), then their influence was stronger. It will be interesting to see how many of these workers remain in the NHS, or whether many move back into less formal organisations.

Public health medicine of course represents the crossover point between medicine and policy, and as such could potentially play a major role in the development of services in the early stages of an epidemic. Yet there is also evidence that community medicine was sometimes unable to secure a firm foothold in the local policy process as a whole after the 1974 reorganisation, and was potentially marginalised as a result of the introduction of general management: 'In some parts of the country community physicians seized the opportunity which was presented to them in 1974 and created vigorous departments which continue to make important contributions to the planning and development of health services for the populations they serve. In other places, some simply failed to make the transition.'[46]

HIV/AIDS should be seen as perhaps the first issue to come along after the introduction of general management which clearly related to the health of populations. How did public health respond to the challenge? The case studies indicate that public health was always important in the early response to HIV/AIDS, but in very different ways. In some cases public health departments represented an empty shell from which front line service developers could operate. Some public health physicians concentrated on the epidemiology rather than the policy. But others became intensely involved in the policy process around HIV/AIDS, writing strategies, bids for funds and distributing resources (although probing for value for money and the reduction of implementation deficits were managerial tasks which were more foreign to them). In some localities public health was itself adapting through its response to HIV/AIDS to the new world of general management, for example, giving the task of planning for service development to a Specialist in Community Medicine (SCM) who would take advice from a group.[47]

Leadership could be supplied from small groups as well as from individuals, and in one locality an effective and cohesive team emerged and was kept together which networked well with local authorities and the voluntary sector. Leadership from such a core group offered a broader base for service development, especially where the group was characterised by a range of complementary skills.

We now briefly consider the question of organisational development and design. While there seems to have been little self-conscious intervention by Organisational Development or Human Resource Departments, nevertheless in a number of the case studies opportunity was taken following the introduction of general management to introduce more flexible forms of decision making better able to process a high change issue. Most obviously the appointment of AIDS co-ordinators could help build lateral networks between specialties and vertical links between District and Units (the most fruitful planning could emerge as a dialogue between the top down and the bottom up) but in some instances more radical organisational change was evident, particularly where more conceptual managers or public health physicians had been drawn into the process.

Sometimes a small mixed advisory group would form around a general manager offering readily accessible advice on epidemiology, service development and finance (as in Bloomsbury's 'kitchen cabinet') which was a small, highly informal group which advised the lead general manager. In one regional centre, the opportunity was taken to construct around HIV/AIDS a new type of project-based Health Promotion Team which (on the basis of careful selection of staff, confidence about team performance and frequent reporting up) was given a buffer space within which to develop in its first phase.[48]

Here the shared and energising values of the team were of key importance. In another regional centre, similar themes of the winning of space within which service development could take place on the basis of securing political support at Chair level emerged. A small core group formed around the product champion as an initial bridgehead into the DHA. Perhaps the principal long-term danger associated with the creation of such small in groups is 'groupthink', so that deviant or heretical opinions are squeezed out, and external groups which do not share such values are labelled as 'bigots', thus narrowing the basis of potential organisational support.

Discussion and implications

A number of general and concluding points should now be made. The substantial local variation found to exist and the major role played by liberal professional elites do not confirm the crude theories of state repression sometimes advanced as a way of understanding the government response to HIV/AIDS. The picture is rather one of 'bounded pluralism'. At DHA level the debate was rather dominated by internal clinical and managerial elites which decomposed into liberal and conservative wings, but little space was accorded either to social movements or elected members. The outcome of these debates was highly unpredictable, depending on the local balance of forces, and just who established the early roles, but there was little evidence of an effective top down political drive to 'put the lid' on AIDS. Indeed, the provision of earmarked funds nationally was a crucial motor of change as significant earmarked sums were won from the Treasury. This potentially could finance significant growth even in inner city districts where services generally were under pressure to contract, although this also depended on the relative ability of the AIDS lobby to retain control of these resources locally, in competition with the finance function. The micropolitics of the District were crucial in the struggle for control over the money.

Secondly, the HIV/AIDS issue also highlights some well-established organisational theoretic themes, albeit in new contexts. The following themes were identified which all relate to various problems caused by the management of growth: processes of service innovation and in particular the nature and role of product champions and product championing; strategy making and the retention of strategic flexibility; crisis construction, management and its aftermath; the organisational politics of budgetary windfalls; and aspects of organisational design and development.

Thirdly, the comparative case study analysis allowed us to test and develop organisational literature. A three-phase model was advanced to explain patterns of crisis management which incorporated a first 'crisis as threat' phase, a second 'crisis as opportunity' phase and a third 'aftermath and burn out phase'. The concept of the clinical product champion was also utilised, and some clinical product champions observed in process. The importance of core groups as well as individuals in supplying leadership was also apparent. On the other hand, the general managerial role was often found to have been dull, albeit with some important exceptions. Only modest attempts had been made to unravel the consequences of HIV/AIDS for organisational development and design and while the introduction of general machinery had facilitated the creation of more flexible decision making machinery, the building up of a strategic flexibility was not on the whole evident.

Finally, there is a question of what happens after this period of rapid change. There were indications that by 1989–90 conditions were beginning to change and that a point of discontinuity was approaching: the period of rapid increase in earmarked funding was coming to an end; 'normalisation' and integration with the host organisation was replacing reliance on specialist services; political and managerial attention had switched to White Paper issues; and some of the early innovators had undergone burn out. The new agenda related both to the stabilisation of the rapid growth which had been experienced since 1985 (middle management capacity underwent strengthening in many of the case study localities) and an awareness that ways had to be found for keeping the momentum going. Second generation districts outside metropolitan centres where caseloads were beginning to approach significant levels were beginning to come on stream (for example some of the regional centres or Outer London DHAs), and even within the first generation sites there was sometimes a search for second generation leadership, either because of burn out or because the focus of development had switched to drugs services or services for women and children. Local histories of the organisational and managerial response to HIV/AIDS will therefore continue to develop in the 1990s, although in a different form from the 1980s.

NOTES

1 The Parkside and Bloomsbury cases were undertaken by Ewan Ferlie and Andrew Pettigrew; the Lothian, Central Birmingham, Oxfordshire and Worcester cases by Chris Bennett and Andrew Pettigrew. The Sheffield case was undertaken by Ewan

Ferlie and Pippa Stilwell, while the South Warwickshire case was undertaken by Caroline Watts.

2 J. Street, 'British government policy on AIDS', *Parliamentary Affairs*, 41 (1988), 490–508; P. Day and R. Klein, *Two Way Signals: The Case of AIDS Policy Making in Britain*, Centre for the Analysis of Social Policy, University of Bath (Bath, 1989). Prepared for the WZB Symposium, 'Signals for Steering Government', Berlin, May 1989.

3 V. Berridge and P. Strong, 'AIDS policies in the UK: a preliminary analysis', in E. Fee and D. Fox (eds.), *AIDS: The Making of a Chronic Disease* (Berkeley, 1992).

4 D. M. Fox, P. Day and R. Klein, 'The power of professionalism: policies for AIDS in Britain, Sweden and the United States', *Daedalus*, 118, 2 (1989), 93–112.

5 E. B. Ferlie and A. M. Pettigrew, 'Coping with change in the NHS: a frontline district's response to AIDS', *Journal of Social Policy*, 19, 2 (1990), 191–200.

6 E. H. Thomas and D. M. Fox, 'AIDS on Long Island: the regional history of an epidemic, 1981–1986', *Long Island Historical Journal*, 1, 2 (1989), 93–111; D. M. Fox, 'Financing health care for persons with HIV infection: guidelines for state action', *American Journal of Law and Medicine*, 16, 1 and 2 (1990), 223–47.

7 A. Downs, 'Up and down with ecology – the issue attention cycle', *The Public Interest*, 28 (1972), 38–50.

8 D. Hunter, *Coping with Uncertainty* (Chichester, 1980).

9 Ferlie and Pettigrew, 'Coping with change'.

10 A. M. Pettigrew, L. McKee and E. B. Ferlie, 'Understanding change in the NHS', *Public Administration*, 66, 3 (1988), 297–317.

11 R. Alford, *Health Care Politics* (London, 1975); Hunter, 'Coping with uncertainty'.

12 P. Arno, 'The non profit sector's response to the AIDS epidemic: community based services in San Francisco', *American Journal of Public Health*, 76, 11 (1986), 1325–30.

13 R. Stewart, J. Gabbay, S. Dopson and P. Smith, *District General Managers and the District Health Authority*, Templeton Series Number 3 (Bristol, 1987).

14 W. Ranade, 'Motives and behaviours in district health authorities', *Public Administration*, 63 (Summer 1985), 183–200.

15 See R. Griffiths, *NHS Management Enquiry* (London, 1983), for the seminal document which first proposed the introduction of a general management function in the NHS.

16 R. Rothwell, 'Intracorporate entrepreneurs', *Management Decision*, 13, 3 (1976), 142–54.

17 B. Stocking, *Initiative and Inertia: Case Studies in the NHS* (London, 1985).

18 Rothwell, 'Intracorporate entrepreneurs'.

19 R. A. Burgleman and L. R. Sayles, *Inside Corporate Innovation: Strategy, Structure and Managerial Skills* (London, 1986).

20 R. Shilts, *And the Band Played On* (London, 1987).

21 J. Dutton, 'The processing of crisis and non crisis strategic issues', *Journal of Management Studies*, 23, 5 (1987), 501–17.

22 Downs, 'Up and down with ecology'.

23 B. Hogwood, *From Crisis to Complacency* (Oxford, 1987).

24 C. F. Hermann, 'Some consequences of crisis which limit the viability of organisations', *Administrative Science Quarterly*, 8, 1 (1963), 61–82; T. D. Jick and

V. V. Murray, 'The management of hard times: budget cutbacks in public sector organisations', *Organisation Studies*, 3, 2 (1982), 141–69.

25 W. H. Starbuck, A. Greve and B. L. T. Hedberg, 'Responding to crisis', *Journal of Business Administration*, 9 (1978), 111–37.

26 Griffiths, *NHS Management Enquiry.*

27 A. Liddell, 'General management in a DHA', in B. Stocking (ed.), *In Dreams Begins Responsibility: A Tribute to Tom Evans* (London, 1987).

28 C. H. Levine, I. S. Levine and G. Wolohojian, *The Politics of Retrenchment: How Local Governments Manage Fiscal Stress* (London, 1981).

29 A. M. Pettigrew, 'Contextualist research: a natural way to link theory and practice', in Ed Lawler (ed.), *Doing Research that is Useful in Theory and in Practice* (San Francisco, 1985).

30 A. Chandler, *The Visible Hand* (London, 1977).

31 A. M. Pettigrew, *The Awakening Giant* (Oxford, 1985).

32 J. R. Kimberly, R. H. Miles and associates, *The Organisational Life Cycle* (London, 1980).

33 M. Pye, 'The challenge of AIDS – towards a model for public health response', in M. Pye, M. Kapila, G. Buckley and D. Cunningham (eds.), *Responding to the AIDS Challenge* (Harlow, 1989).

34 In one District, there was a vivid folk memory around hepatitis B which transferred across to HIV. As one respondent put it: 'Hepatitis B hit us and we had about 29 patients and a lot of them died, we lost two members of the medical staff, not actually our own staff, we lost a nurse, we lost a lab technician, people were very worried about it . . . People were really very anxious, it was like a medieval plague city.'

35 In Paddington, realisation over the 1983 August Bank holiday weekend that the number of patients was beginning to escalate, and that media interest was apparent, led the Control of Infection Officer to call an emergency meeting with two clinical academic colleagues to draw up control of infection guidelines to combat rising staff hysteria:

> This caused a lot of tension and pressure because we could not get other people to take it seriously. We knew that we were going to have real patients and real problems, and people seemed to flip between not being bothered and not caring, and it was something minor and peripheral, to being something that was so serious that it was untouchable.

36 A key article is J. F. Peutherer, E. Edmond, P. Simmonds, J. D. Dickson and G. E. Bath, 'HTLV-iii antibody in Edinburgh drug addicts', *Lancet*, 2 (1985), 1129–30.

37 For example, in one regional centre, one respondent said:

> Here we are with a well resourced, properly thought out project, perhaps at just the time when people think 'well, it never really happened did it, the AIDS epidemic in Britain? . . . ' now more than ever we are in a position to provide quite detailed programmes for AIDS education at a time probably when not many people want it.

38 Staff sometimes took on extremely high workloads which proved unsustainable. As one Paddington respondent put it: 'By mid-1985, we were a publishing house, a health education house, as well as a treatment house, and we were very rapidly becoming exhausted.'

39 Kimberly, Miles and associates, *The Organisational Life Cycle.*

40 For example, a number of special teams sprang up in one regional centre. As one member of staff there put it:

> I've never been able to work with so little answerability to any management structure and so little documentation of decisions . . . this is partly because of the sort of person that [the Director] is, he just keeps saying 'Go ahead and do it and we will sort out the mess afterwards', which I find I can cope with . . . I see the whole thing having worked very much on personalities and philosophies, and not on meetings and seminal documents at all.

41 A good example is the change in the nature of the District HIV/AIDS Action Group in late 1988 in our analysis of a low prevalence District:

> The arrival of new people is also likely to influence the nature of the Action Group. Two of the people who were most committed to it have left, and the feeling of being an informal ad hoc group with a shared goal is likely to be replaced by pressure for it to become a more formal, structured, group.

42 E. B. Ferlie and L. McKee, 'Planning for alternative futures in the NHS', *Health Services Management Research*, 1, 1 (1988), 4–18.

43 H. Mintzberg, 'Patterns in strategy formation', *Management Science*, 24, 9 (1978), 934–48.

44 For example, one manager moved some eight miles in 1985 from an Outer London Borough DHA to become the first District General Manager (DGM) in Paddington and was propelled into a new world:

> The funny thing was that AIDS had not impinged on my consciousness at all until I got the job here . . . I became aware that (a) there was such a thing as AIDS and (b) that Paddington and North Kensington was in the thick of it. And then I got here, it went WROOM!, from that moment on, more and more time was taken up. I sat on the AIDS subgroup just to get the hang of it, and it was clear that it was getting bigger and very soon a district ethic that AIDS is important takes over.

45 One worker in a health education team in a regional centre described how personal platforms changed between 1987 and 1989:

> So I think that it was important that the homophobia, racism, and sexism were confronted . . . it was not actually until I had been in the work for a few months that I began to think about people as a group of real people who were depressed and stigmatised and needed support, which would be my platform now.

46 *Public Health in England: The Report of the Committee of Enquiry into the Future Development of the Public Health Function* (London, 1988).

47 As another respondent managing an innovatory team put it in describing the new form of management arrangement adopted: 'That is another implication, we went for the Griffiths 1 idea that jobs were given to people, not groups, those people then discharged that task. If they wanted to call together a group to help them do it, that was fine.'

48 As another respondent in the same District described the new team: 'Never before has there been a project like this, never before has a Health Promotion Project regularly kept the Health Authority updated on its every move in the way that this did.'

11

A fall in interest? British AIDS policy, 1986–1990

JOHN STREET

Introduction

Many of the problems which face a society never disappear completely, but political interest in them often does. Political attention spans rarely do justice to the issue at hand. In 1972, the political scientist Anthony Downs described the 'issue attention cycle' that then applied to environmental issues. The cycle was characteristic of most public problems. 'Each of these problems suddenly leaps into prominence, remains there but a short time, and then – though still largely unresolved – gradually fades from the centre of public attention'.[1] This thought has become so common that it is now enshrined in the title of a textbook on British policy making: *From Crisis to Complacency*.[2] There is a strong temptation to fit this conventional wisdom on to British AIDS policy.

The story would run something like this. From 1982 to late 1986, a sense of panic gradually developed within government. The spread of AIDS came to be seen as a 'threat' for which crisis action was needed. This impression was fostered in the pages of tabloid papers, and in a wave of television documentaries. The government had to be seen to act. A special Cabinet Committee was created, the budget for public education was vastly increased, as was research and treatment funding; television adverts were broadcast and every home received a leaflet explaining how AIDS was spread and how it could be avoided. And then, just as suddenly, AIDS disappeared from the front pages of the papers. Politicians no longer rushed to talk about it. Or when they did, it was to wonder aloud whether the threat had not been exaggerated. In 1989 the special Cabinet Committee was wound up. It seemed that political interest in AIDS had indeed run the familiar course from crisis to complacency.

Part of the purpose of this chapter is to assess this version of the later history of AIDS policy, to ask whether in fact it has been dropped from the political agenda. I want to set this examination against a more general backdrop: the way in which party political values and interests have played their part in the form and content of AIDS policy in Britain. The story of the passage from crisis to complacency is, after all, a story about politicians and the way they behave to protect their personal and party interests. It suggests that the attention span devoted to an issue is determined by the electoral cycle and by cynical political calculation.

Though the crisis-complacency model is tempting, it needs to be treated with caution. A clear distinction has to be made between party politics and policy making. The fact that political interest may wane does not mean that policy interest will follow the same course. It might flourish precisely because political interest has faded. Equally, we need to avoid conflating the public, media-generated profile of an issue with the actual development of the policy process. The attention span of the media and the public is much shorter than that of policy makers, and is determined by quite different interests and criteria. Nonetheless, the thought that AIDS may have lost political support and commitment cannot be discounted *a priori*; we need to look closely at the trajectory it has followed since the 1986 watershed.

This paper, therefore, has two tasks. The first is to look critically at the history of AIDS policy after 1986. The second is to explore the ways in which political interests have shaped that history. To make these tasks more manageable, I have narrowed the focus. The account of AIDS policy begins with the work of the House of Commons Select Committee on the Social Services. Its 1987 report was, at the time, the most comprehensive statement on AIDS policy in Britain. In the context of this paper, it not only provides a critical perspective on AIDS policy, it also acts as a guide to political opinion on AIDS. Using the Select Committee Report enables me to examine government performance in the political climate of the time. After all, the Select Committee is itself part of the policy process and an expression of the political values and interests at play in the response to AIDS. Although the Select Committee system encourages the development of cross-party consensus, it does not produce objective analysis. Political compromises and trade-offs are built into the committee's work. It establishes a common ground for MPs concerned about their role as representatives, parliamentarians, careerists, party loyalists and ideologists. The Select Committee Report, therefore, represents a political benchmark against which to measure changes in government policy. It does not set an absolute standard, rather it provides a way of assessing the development of AIDS policy in the period after 1986.

The focus of this paper's second task – the examination of political influence – is narrowed by concentrating on the elite policy process, on the way in which political values in the core executive influenced the outcome. Rather than looking at the policy process as a whole, therefore, my concern is with the way in which political judgements were included or excluded from the decisions being made about the response to AIDS. Were decisions about AIDS policy inspired by party political calculation?

The government's response to AIDS 1986–90

The dramatic announcement in November 1986 that the government was to commit itself to tackling AIDS did little to change the basic components of existing policy. These remained the four elements of: (a) public education; (b) treatment of those with AIDS; (c) prevention of the spread of HIV; (d) research into the causes and cures for AIDS. While the basic policy strategy was unaffected by the 1986 political intervention, there were major shifts as a result of it. Most obviously each benefited from a substantial increase in resources – the public education campaign gained by £20 million, for example. It also altered the political profile of, and responsibility for, the policy. Before then AIDS policy was largely the business of the health authorities, the Department of Health and a number of other interested parties (from the Terrence Higgins Trust to the Medical Research Council). The creation of a special Cabinet Committee was a way of expressing the new commitment, giving public attention to the policy and adding another layer of control. It also added to the political capital invested in AIDS. Cabinet Committees have long been regarded as the main centres of power in the executive, but they have also been kept as official secrets. The AIDS committee, by contrast, was launched in full public view. The combination of power and publicity provided the means for introducing major changes. And there was certainly, as the Select Committee on the Social Services heard, a need for change.

Criticisms of AIDS policy 1986–7

The Select Committee heard evidence from many different sources when it scrutinised British AIDS policy in February–March 1987. Witnesses testified about every aspect of the policy, from the way it was made to the way it was implemented. The Committee's conclusions were published in May 1987. Although it was generally complimentary about the government's response, the Select Committee voiced a number of criticisms. These criticisms fell into two categories. One set of comments was directed at the way the problem of AIDS was being assessed, in particular how it was spread and the extent of its spread. The other set of criticisms focused on the content of the policy itself.

The Committee's first line of criticism, therefore, was directed at policy formulation. It argued that too little had been done to discover what sexual practices were engaged in by men and women, and how that behaviour, where risky, might be changed. Too much attention, it was said, was given to medical and clinical research, and too little to sociological research.[3] At the same time, the Committee was critical both of the funding of basic research and clinical research.[4] These gaps in knowledge were compounded by the government's reluctance to use the voluntary sector, especially the Terrence Higgins Trust.

The other main line of criticism focused on policy implementation. Doubts were raised about whether the public health campaigns were sufficiently explicit and whether they were reaching their targets.[5] These comments were fuelled by a general scepticism about whether sexual behaviour was being changed by the posters, television advertisements and school packs. If government, the Committee said, was unhappy about spreading a more explicit message, then the task should be handed to the voluntary sector.[6]

The Committee also argued that the government should expand the range and funding of treatment services – from genito-urinary medicine (GUM) clinics, to counselling, to community care.[7] This advice was combined with a demand for more prevention work. The government ought to promote the use of condoms, albeit 'only in the most general sense', and to encourage the development of needle exchange schemes, beyond the few existing experimental local schemes, and develop schemes in the prison system.[8] Finally, the Committee wanted the government to do more to protect the rights of those people who were HIV positive or who had AIDS.[9] The insurance industry was the main target. The Committee complained that not only did insurance companies insist that people reveal whether they had been tested for HIV, they also retained the right to refuse cover to those they deemed to constitute an unacceptable risk.[10]

Although each of these criticisms called for particular actions to correct them, the Select Committee argued that there was a general weakness underlying the government's response to AIDS: the lack of central co-ordination. Despite the creation of the AIDS Cabinet Committee, it was argued that policy making was made in a pragmatic, *ad hoc* fashion.[11]

In summarising the Select Committee's critique, I do not want to pretend that these were the only criticisms to be made of government policy in 1986–7. What they constitute, however, are the criticisms to which the political leadership was most susceptible. They were ones to which there was a direct, if vague, responsibility to respond. The same was not true, for instance, of the criticisms coming from gay activists or the moral right. Neither of these groups had established connections with the political elite, although, as we shall see, the moral right had an important ally in Mrs Thatcher. The Select Committee's criticisms expressed a highly mediated version of public opinion and a more direct expression of electoral political interests. It helped to set the political climate which enveloped AIDS policy making and which established an agenda which the government could either respond to or ignore. Hence, it establishes a basis from which to ask whether the Thatcher Cabinet's crisis response faded into complacency.

Appeasing the critics?

Before looking at the specific criticisms, we need first to look at the general problem with which the government was dealing: the spread of HIV and the incidence of AIDS.

The figures in Table 1 tell a complicated story, from which few conclusions can be drawn. It is difficult to make sensible comparisons between the period before and after 1986. The data are more accurate in the latter period, thereby creating an impression of increase in the spread. Similarly, the incubation period between infection and the development of AIDS also distorts the later picture. It seems that the rate of increase from homosexual contact is much lower than that for drug users, albeit with much smaller absolute figures. While increase in homosexual spread fell from 91% in 1986–7 to 40% in 1988–9, the number of infected drug users has increased by 100% each year since 1986. There is no sign of a downturn in the heterosexual spread, although importantly the main contributor to the increase is exposure to HIV abroad. The figures in themselves, though, only reveal the general conditions under which the policy process is analysed. They tell us little about what contribution, whether positive or negative, the policy itself makes. This is a general problem of the study of AIDS policy. In a recent review of AIDS policy throughout the world, Mildred Blaxter comments: 'given the variety of . . . background variables, together with differences in the magnitude and nature of each country's epidemic, overall "success" or "failure" of policy can barely be judged, much less accounted for'.[12] Here, all we can do is compare one political response to another, the Select Committee's to the government's.

Policy formulation since 1986

There has undoubtedly been a marked increase in research into and knowledge of sexual behaviour. This research, begun in the mid-1980s and financed mainly by the Medical Research Council, is being published and disseminated.[13] The store of knowledge is likely to expand, at least in the short term, because of work underwritten by the Economic and Social Research Council (ESRC). The responsibility of the government in promoting this change is, at best, ambiguous.

While the Economic and Social Research Council's involvement in AIDS research can itself be seen as a consequence of the issue's change in political salience in 1986, its contribution has been hedged in by political constraints. Throughout the decade of Mrs Thatcher's rule, the ESRC felt vulnerable. The knowledge in which it traded was not highly valued by Conservative ideologues, who tended to see social science as socialism under an academic guise. The ESRC, which depended on the government for its funds, was therefore circumspect about the research it funded. Thus, when in 1985 it was asked to support

Table 1. *People with AIDS*

Category	1983	1984	1985	1986	1987	1988	1989	1990
Homosexual/bisexual	25	93	245	538	1,032	1,634	2,288	3,234
Intravenous drug abusers			2	9	19	39	80	161
Homosexual/bisexual + IVDA				6	19	31	38	61
Haemophiliac		3	9	25	70	127	169	228
Blood recipient								
Abroad			5	6	16	20	26	37
UK			5	4	8	15	21	30
Heterosexual contact								
Partner with above risk factor						15	22	34
Others abroad		6	11	14	35	54	100	208
No evidence of exposure abroad				4	9	19	13	26
Child of at risk/infected parent				3	13	19	23	36
Other	6	5	1	1	6	21	50	43
Total	31	108	280	610	1,227	1,994	2,830	4,098

Source: Department of Health.

research into gay sexual behaviour and the spread of HIV, it rejected the project on the grounds that it did not accord with the Council's research priorities. (The work was subsequently financed by the Medical Research Council (MRC)). The ESRC made no further effort to solicit or direct AIDS research until the 1986 political watershed. Subsequently, in the summer of 1988, the ESRC announced that it was making £1.9 million available for three years of AIDS research, particularly in the area of sexual behaviour.

The value of this new commitment has, however, to be qualified. Despite encouraging the thought that more money would be available in subsequent years, the ESRC has in fact added nothing to its original commitment. And the government has done nothing to cause a change of heart. Quite the opposite. A planned National Survey on Sexual Behaviour, to be financed jointly by the ESRC and the Department of Health, was cancelled. Two sets of decisions were involved, one in Downing Street the other in the ESRC.

It was widely reported that Mrs Thatcher was personally responsible for vetoing the survey. The proposal for the survey had been held in Whitehall for several months. It needed formal approval because it involved the commitment of resources. While such a decision would normally fall to the relevant department, the style of Mrs Thatcher's leadership entailed her frequent involvement in relatively small matters of particular concern. The survey was one such matter. Her biographer, Hugo Young, records his impression of the event: 'The Prime Minister's veto on public money appeared to derive from an instinctive distaste for invasion of heterosexual privacy – although homosexuals were fair game. Her decision was never explicitly defended. It simply happened, without a public rationale and without the relevant minister, in possession of the scientific facts, feeling able to challenge it'.[14]

The Department of Health backed out, leaving the ESRC on its own. Formally, the ESRC could have continued with the survey. It, after all, was responsible for its design and conduct. But it lacked the necessary resources, and without political support, it too withdrew from the enterprise. If the fortunes of the ESRC were taken as a test of the government's determination to increase knowledge about sexual behaviour, then we might conclude that its will was weak. But the reason for the lack of determination seems to owe less to complacency or indifference, and rather more to an excess of concern.

The government has, however, made some attempt to improve the monitoring of the spread of AIDS, if not the behaviour that causes it. After much prevarication, the government conceded the need for a more systematic mapping of the spread of HIV. From January 1990, it introduced a limited system of anonymous screening. In doing so, it acceded to demands that had been voiced for some time. It seems to have occurred through the collapse of counter arguments, rather than the emergence of any positive initiative. One of the obstacles to be surmounted was the Select Committee's Report which opposed screening, largely on the strength of the ethical arguments of Ian Kennedy, a Professor of Law at King's College, London.[15] It was significant that when the government introduced screening, it spoke of the absence of legal or ethical constraints.[16] These words were uttered at a time when Kennedy himself had become part of the government's own Expert Advisory Group on AIDS, although he had not changed his position on screening. It seems, though, that this advice did not carry the Committee. Perhaps this is not surprising, the advisory system continued to be dominated by medical expertise, albeit mediated by the departmental secretariat.

The exclusivity of the advisory system is further demonstrated by the treatment of the voluntary sector. The Terrence Higgins Trust, Body Positive and other such groups have remained on the outside, although the grants they receive from central government have increased.[17]

Importantly, though, these grants contribute only a portion of the organisation's operating costs, and are only awarded on an annual basis. The groups' position, therefore, remains precarious, and may become more so with the 1991 reforms of the NHS which makes it necessary for agencies to compete for contracts and funds.

Although the 1986 watershed signalled an increase in funds for voluntary groups, it has done little for the access granted them. If anything, the political attention actually led to a decrease in outside advice. The demise of the Health Education Advisory Group exemplified this trend.

The Health Education Advisory Group (HEAG) was set up in the mid-80s by the Chief Medical Officer to advise on prevention policy, about which he had little direct knowledge. The HEAG was in some respects a normal advisory group, and in others an exception to the rule. It was an exception in that it contained a social scientist, Professor Tony Coxon, a sociologist who specialised in research methodology and a member of the Gay Research Group. HEAG also contained representatives of Body Positive and the Terrence Higgins Trust, as well as a member of the Gay Medical Association.

The HEAG undoubtedly made an impact in the early days of AIDS public education. The Department of Health was uncertain about how to proceed. One official thought that the two key public health messages should be: 'avoid London' and 'avoid male prostitutes', neither of which addressed the real problem. The HEAG persuaded Acheson to focus on condoms. The secretariat obliged by furnishing the Group with extensive documentation on condom promotion campaigns throughout the world (including Australia's 'rubber dubber' campaign). HEAG managed to force the Department to make its campaigns more explicit and to give greater prominence to the use of condoms.

The HEAG, however, eventually fell into disuse. There were a variety of reasons for this. The HEAG's influence was, it seems, inversely proportional to the political interest taken in their work. As political responsibility for public education increased, so expertise became more selectively chosen, and groups like the Terrence Higgins Trust (THT) pushed to one side.

It was not just politics, though, that limited the effect of HEAG's advice. The character of that advice also mattered. The HEAG was not offering hard science, instead its advice was grounded in psychology and the study of social behaviour. This type of knowledge tended to be viewed as 'common sense', despite the evidence to the contrary. Reflecting upon his experience on the HEAG, Professor Coxon remarked: 'The feeling I have, particularly, was that there was a very strong mix of concern and expertise which, in the event, was not actually used and that whilst in particular medical skills were being called upon and used and respected, other sorts of non-medical skills were being ignored'.[18] The HEAG was replaced by advice from a more selectively drawn body, Coordination of AIDS – Public Education (CAPE). CAPE was made up of the Health Department, health education agencies, the Health Education Authority (HEA) and interested government departments. In short, CAPE represented the dominant consensus.

Policy implementation since 1986

The government has continued to increase the funding for education campaigns (£44 million was allocated in 1986–9). Equally important, responsibility for public education shifted from the Department of Health and the Health Education Council, to the Health Education Authority. The HEA was granted considerably more power and more resources than its predecessor. But, like the ESRC, the gain in the HEA's profile was paid for in increased policy scrutiny.

The content of its campaigns have had to pay heed to the character of the political climate. Dr Mukesh Kapila, Deputy Director of the HEA's AIDS programme, summed up the effect of political involvement:

> it is clear that UK government leadership has been an important driving force to get things going and, in general, our politicians have made wise decisions. But it is also true that in countries in which political expediency dictates social policy, the personalities and personal beliefs of key individual politicians and civil servants have profound influence on how programmes evolve, including their tone, credibility, public and professional acceptability and ultimately their impact.[19]

When the HEA's special AIDS unit was wound up in 1989, it was surmised that this signalled further evidence of political interference and a wariness about the tone of public education campaigns. This charge is denied by both the HEA and the government. What cannot be overlooked, however, is that the HEA's education campaigns are shaped by more than simple disinterested concern for getting its message across. In education policy, political factors played their part in constraining policy, but in other policy areas, politics had a different effect.

Like spending on education, the money made available for AIDS treatment (and related services) rose markedly in the period from 1986, especially when set against the provision for other parts of the health service. The government's formal (ideological) position was that problems could not be solved by throwing money at them. With AIDS, though, this was precisely what they seem to have done. Operating against the formulas normally applied to the allocation of funds within the National Health Service (NHS), the government underwrote 70% of the costs centrally. As a result of this beneficence, the genito-urinary services have been immeasurably improved both physically and in terms of the service they offer. The inequities in the allocation have not, however, changed (see Table 2). AIDS patients are costed differently in different parts of the country. The explanation for this distribution was not discrimination between regions, but, it was claimed, the *ad hoc* and inefficient character of the allocation system.

Whatever the gaps in the response on the treatment front, it is in marked contrast to the way the government has moved on prevention. The bulk (more than 90%) of the funding has been concentrated on the health authorities. For critics, this has been an inefficient use of resources because health authorities are ill-equipped to work with other agencies and at reaching key groups, a problem made all the greater by the health authorities' general reluctance to give prevention a high priority.[20]

Change in prevention policy has been slow and selective. A considerable battle had to be fought, mostly by the government's own Advisory Council on

Table 2. *Allocation of funds per people with AIDS (PWA) for different regions (1989)*

Region	Allocation per PWA (£s)
Yorkshire	52,500
Trent	58,000
East Anglia	75,000
Oxford	72,500
Mersey	49,500
Lothian (Scotland)	20,000

the Misuse of Drugs, before there was any increase in commitment to needle exchange schemes. A change of minister was also necessary to expedite the process. The system of needle exchanges continued to depend upon regional initiatives, and, as a result, reflected local practices and policies. Little or nothing was done about increasing the availability of condoms. If anything, things got worse, following cutbacks in the Family Planning Association. Meanwhile the Home Office steadfastly refused to allow needle exchanges or condoms to be introduced within the prison service.

Finally, despite the protests of groups like the Terrence Higgins Trust and the criticisms of the Select Committee, the government has been unwilling to intervene in the activities of the insurance industry. The government's only concession has been to agree to meet the industry representatives to discuss the policy. This was, it seems, a mere gesture, because the government was already convinced of 'the need of the insurance industry to find out relevant information before providing life insurance'.[21]

Summary

AIDS policy since the 1986 watershed has clearly changed, but the question is how these developments should be assessed. Do they demonstrate a decline in the interest-attention cycle and a rise in complacency? Certainly, they have not formed part of a clear political strategy. The lack of co-ordination that concerned the Select Committee in 1987 has not been corrected. The only gesture towards central planning, the special Cabinet Committee, ceased to operate after September 1989. Since then political control of AIDS policy has largely reverted to the various agencies responsible for its implementation. This does not mean, however, that politics has ceased to influence AIDS policy and to determine its fortunes. The absence of central co-ordination or of deliberate strategic planning is not proof of political indifference. It merely indicates that there is no single route through which that interference is organised. The rest of this chapter, therefore, explores the way in which political judgements and interests have shaped AIDS policy and determined whether complacency has ruled.

Politics and AIDS policy

The impact of politics on AIDS policy has taken many forms and emerged from many different sources. It has sometimes been direct, sometimes indirect; it has been the result of individual initiative, or the playing out of structural processes. What follows is by no means a comprehensive picture. Instead it aims to explore the different general ways in which policy and politics have intersected. We begin with the most politically obvious form of influence, that exercised by Mrs Thatcher.

The impact of Mrs Thatcher

The decade since AIDS first appeared in Britain has coincided with the era of Thatcherism, in which the British political agenda and British political practices were significantly altered. The temptation is, therefore, to see AIDS policy as the child of Thatcherism and of the person from whom the era took its name. Such a response is too easy.

One of the most distinctive features of Mrs Thatcher's influence on AIDS policy is her apparent *lack* of interest. When the special Cabinet Committee was established, the job of chairing it was given to her deputy, Lord Whitelaw. And on his resignation it went to the even more junior John Moore. Students of Mrs Thatcher's style of government have observed that when she wanted to impose her will, she chaired the relevant Cabinet Committee. With AIDS policy, she remained at one remove from the political centre and she made very few public statements on the subject. When she did comment, it seemed that she thought that countering AIDS was really the responsibility of the individual citizen, not the government.

Of course in taking such a view and remaining distanced from policy making, she was having a political impact; she was refusing AIDS the kind of support that other policies enjoyed. And when she did intervene directly, it was to dull the policy. Not only did she undermine the national survey of sexual behaviour, she also caused health education campaigns to remain cautiously inexplicit. It was also possible to detect her influence on the ministers directly responsible for AIDS policy. The reluctance of the Department of Health to expand the needle exchange scheme seemed to owe something to John Moore's unwillingness to take the political risks involved. There is, though, another dimension to Mrs Thatcher's mixture of indifference and interference. Where she chose not to get involved, she allowed, albeit by default, the emergence of policies which accorded with liberal thinking on AIDS and which allowed for more funding than might otherwise have been available. In so far as decisions on AIDS were being made away from Mrs Thatcher's gaze and the political limelight, it was possible for them to reflect the consensual approach that the Department of Health officials and their ministers were disposed to follow. In short, Mrs Thatcher's indirect impact had two dimensions. Her values and presence created a climate which ministers felt inclined to acknowledge. This restricted the development of some aspects of AIDS policy. At the same time, her decision to remain aloof allowed for progress in other areas.

The extent of her direct influence was eloquently demonstrated by the impact of her departure. Her successor, almost immediately, reversed her policy on compensation for haemophiliacs. In doing so, John Major showed that political intervention need not work negatively. It does, though, suggest that the calculations upon which intervention is based do not derive directly from rational assessment of the policy problems. The attention and resources devoted to public education campaigns have been much greater than those devoted to research (approximately £62 million has been spent on publicity; £50 million on research). While this imbalance may owe something to the nature of the problem, it also owes much to the fact that the education campaign provided an easier demonstration of political action. For the ambitious minister, it provided a route to popular attention. A similar rationale might be ascribed to the decision to make payments to the haemophiliacs with HIV. Not only had the Haemophiliac Society lobbied MPs very effectively, it also offered a group of people who could be portrayed as 'innocent victims' demanding public sympathy and political action. Haemophiliacs, in this sense, were turned into a good party political issue.

The politics of the policy process

Political influence, though, can be exercised without the deliberate intention or intervention of individuals. It can simply be the consequence of particular political relationships, such as existed between the government and the Health Education Authority. In early 1990, a series of advertisements was run on prime-time TV. They had the same black and white format: a single talking head. The budget was £2.3 million and the campaign ran for six weeks. The talking heads were all experts in the AIDS field: Sir Donald Acheson, Professor Michael Adler, Dr Anthony Pinching, Dr Anne Johnson, Dr Raymond Maw and others. Each uttered a simple statement about HIV and AIDS. The Chief Medical Officer, for example, said: 'We know for certain that HIV, the virus that causes AIDS, can be spread by sexual intercourse from man to man, man to woman and from woman to man. It is also spread by sharing infected needles and syringes during drug abuse.' It was, said the HEA, a very successful campaign.

But why was this low key approach adopted? Partly it reflected a changing perception of the problem of AIDS, from that of an immediate crisis to that of a long-term policy. But there were more direct, political causes for the change of tone. There had been renewed media interest in AIDS. This time it took the form of scepticism about the heterosexual spread. The *Sunday Times* serialised the book by Michael Fumento[22] which cast doubt on the idea of 'heterosexual AIDS'; the same theme was taken up by various people in the letter columns of the 'serious' press; and a television documentary gave publicity to the Californian scientist, Professor Duesberg, who claimed that HIV was not the cause of AIDS. This new interest in the disease coincided with reports of the scrapping of the HEA's AIDS unit.[23] It also coincided with a decline in the political fortunes of the Conservative government, as it trailed behind Labour in the opinion polls. This made the government politically sensitive to anything that might detract further from its popularity, a popularity that it had chosen to build around the family and morality.

It was in this political climate that the HEA advised the 'experts' campaign. It was designed both to maintain the credibility of the HEA and its message, conveying the necessary information in an unsensational fashion. The campaign, in short, was informed as much by the politics of the day as by the spread of the disease.

A parallel form of political influence could be detected in the advisory system which played such a vital part in determining how the 'problem' of AIDS was defined. This was evident in the experience of the HEAG, but it also seems to be true of the way in which the Expert Advisory Group on AIDS was used. The Department of Health's secretariat played an important role in determining what issues were considered and what solutions were advanced. It was through the secretariat that political boundaries were set. Equally significant, however, was the way in which the personnel of such organisations were dominated by certain types of knowledge and interests. Primarily, it was clinical medicine that established the general concerns of the advisory bodies.[24]

Finally, it is worth observing how parliament responded to AIDS. Although Parliament plays a relatively small direct part in the political process, it does contribute to the political capital invested in outcomes. Where some issues – like *in vitro* fertilisation – have become a source of intense political concern, causing problems within the policy process, AIDS has remained remarkably free of blatant political axe-grinding. If anything, it has been characterised by parliamentary indifference. The main debates on AIDS have been sparsely attended. Parliamentary questions have come from a very limited number of MPs, and almost always from people with a genuine concern for the adequacy of the government's response. One explanation for this political quiescence lies with the role taken by the All-Party Committee on AIDS. The All-Party group has helped to build a consensus around AIDS which has been reinforced by the consensual practices of the Select Committee. It has created a barrier against the emergence of maverick self-publicists who might have been tempted to make political capital out of the disease. Attempts within Parliament to raise doubt about the heterosexual spread of AIDS have met with little sympathy or support. This is not to deny that political interests and values have played a part in the parliamentary consensus on AIDS. There has been a clear attempt to manage opinion and to forge agreement around a containment strategy. In doing this, party politics have been of relatively little importance, and it is a more general corporatist politics that has counted. The attempt has been to fit AIDS into existing political and administrative operating procedures, and to avoid the kind of radical politicisation favoured by the political fringes, whether represented by gay groups like Outrage or the Conservative Family Group.

The impact of other policy issues

The role of politics in AIDS policy cannot be confined to the specific policy arena. The emergence of AIDS policy coincided with a number of other important political changes which had an impact upon its course and its effect. The two most obvious of these were the reforms to local government legislation and to the health service.

While the formal position of the Department of Health was that of equal concern and care for all who had AIDS, there were other messages also emanating from central government. A general disposition in favour of the 'traditional family', together with a particular animosity to homosexuality, was apparent in Conservative rhetoric. Within AIDS policy, this found expression in the idea that haemophiliacs with HIV were 'innocent victims', the implication being, of course, that other people were responsible for their plight. Outside AIDS, such attitudes were confirmed in Section 28 of the Local Government Act which sought to outlaw the 'promotion of homosexuality'. By sanctioning homophobia in this way, the government threatened an important element of AIDS policy: to encourage openness and equality in the response to the disease.

The delivery of AIDS policy has also been threatened by another feature of government policy: the reform of the National Health Service. Although the full implications of these reforms are only slowly emerging, those who worked with AIDS saw the devolution of responsibility for health care and the system of contract provision as undermining some of the principles which previously shaped AIDS health care. They warn that GPs may be reluctant to take on HIV positive patients because of the costs thereby imposed on drug budgets; that the co-ordination of other services will become increasingly difficult because of the complex contracting arrangements to be established; and that voluntary groups like the THT will have to compete for scarce funds with statutory services.[25] Whether or not these expectations are borne out, it is clear that AIDS policy is not immune to political decisions taken elsewhere, and that those decisions have sometimes worked against AIDS policy.

Conclusion

This chapter began with the question as to whether AIDS policy has suffered the same fate as is typically attributed to other policies born of crisis. Has that crisis led swiftly to complacency as Downs's 'issue-attention cycle' is played out? In trying to give an answer, two riders were introduced. The first involved clarifying the different aspects of policy that might be involved in the passage from crisis to complacency – ebbs and flows in public and party opinion do not translate neatly into similar movements in the policy process. The second rider was to suggest that the measure of shifts in interest was to be found in the politics of the policy process, the way in which values were imposed and interests organised.

The evidence discussed here indicates that no simple generalisation, whether it refers to attention cycles or to crisis-complacency continuums, can be applied. Public opinion, as measured by media coverage, has fluctuated and taken a variety of forms. AIDS, though, remains a public issue. Equally, party political opinion has followed no straightforward pattern, and has in any case to be explained more by the activities of groups like the All-Party Committee on AIDS than by some 'natural law' of politics and policy making. The same is true of the government. While it has not met the demands made by its critics, in particular in the Select Committee on the Social Services, it has amended and developed its AIDS policies over the period since the 1986 watershed. Moreover, these changes cannot be attributed to a decline in political interest or in response to fluctuations in public opinion. Explicit political intervention, and less direct forms of political influence, have been a constant feature of the way the AIDS 'problem' has been defined and responded to.

Superficial impressions of a decline in AIDS' political salience have to be heavily qualified by the realisation that AIDS policy continues to be subject to changes of political leadership and political circumstances. Its fortune owes less to any 'law' of political behaviour and much more to the playing out of complex political processes, in which party political interests, ideology, 'expertise' and many other factors intersect. Any impression of a 'cycle' is undercut by the realisation that shifts in interest and changes in policy are to be accounted for by detailed analysis of particular circumstances, in which the electoral process is but one element. The fluctuating passions of politicians are a poor guide to the operation of the policy process; at the same time, political values and interests can never be eliminated from the creation and implementation of policy.

Acknowledgements

This chapter draws on research financed by the University of California and carried out with Professor Albert Weale at the University of East Anglia; he also helped with this paper, as did the editors of this volume. They are absolved of blame, but are due much thanks.

NOTES

1 A. Downs, 'Up and down with ecology – the "issue attention cycle"', *Public Interest*, 28 (1972), 38.

2 B. W. Hogwood, *From Crisis to Complacency? Shaping Public Policy in Britain* (Oxford, 1987).

3 Social Services Committee, *Problems Associated with AIDS*, vol. 1, HC 182–1 (London, 1987), para. 51.

4 *Ibid.*, paras. 23 and 26.

5 *Ibid.*, paras. 61–2.

6 *Ibid.*, para. 65.

7 *Ibid.*, paras. 111–12, 113–14 and 133–6.

8 *Ibid.*, paras. 78, 86 and 95.

9 *Ibid.*, paras. 167–70.

10 *Ibid.*, paras. 178–80.

11 *Ibid.*, paras. 181–5.

12 M. Blaxter, *AIDS: worldwide policies and problems* (London, 1991), 32.

13 See, for example, P. Aggleton, P. Davies and G. Hart (eds.), *AIDS: Individual, Cultural and Policy Dimensions* (London, 1990).

14 H. Young, *One of Us* (London, 1990), 548.

15 Social Services Committee, *AIDS*, HC 202 (London, 1989).

16 Department of Health, *AIDS*, Cm. 925 (London, 1989), para. 14.

17 Grants to the Terrence Higgins Trust: 1985–6, £35,000; 1986–7, £100,000; 1987–8, £300,000; 1988–9, £400,000.

18 Social Services Committee, *Problems with AIDS*, vol. 2, 35.

19 M. Kapila, 'AIDS prevention through public education: the work of the Health Education Authority', *Royal Society of Medicine: The AIDS Letter*, 15 (1989), 3–4.

20 V. Beardshaw, 'Blunted weapons', *New Statesman and Society*, 2, 78 (1989), 24–5.

21 Social Services Committee, *AIDS*, para. 19. Meanwhile, evidence emerged that an increasing number of people were refusing to be tested for HIV for fear of the consequences of their insurance status.

22 M. Fumento, *The Myth of Heterosexual AIDS* (New York, 1990).

23 Health Education Authority, *AIDS and Sexual Health Programme: Summary of Second Annual Report* (London, 1990), 7.

24 This argument is more fully discussed in J. Street and A. Weale, 'British AIDS policy', in R. Bayer and D. Kirp (eds.), *AIDS in the Industrialized Democracies* (Rutgers Press, 1992).

25 C. Bentley and M. Adler, 'Choice cuts for patients with AIDS?', *British Medical Journal*, 301 (1990), 501–2.

12

AIDS policies in France

MONIKA STEFFEN

AIDS is a difficult health issue which mainly concerns medicine, hospitals and public health policies. But the epidemic also concerns the political system. The definition of the nature of risk and of the rank it should occupy amongst the different risks society may be facing is a political task. A new problem and its possible consequences can be evaluated in many different ways. Different social groups will develop various conceptions of the problem according to their position in society and of the danger it may present for them and for society as a whole. Therefore, negotiation is needed between different possible perceptions of the problem and a large consensus is necessary to make the choice legitimate. Priorities as defined will automatically legitimate certain actors and certain means to deal with the problem and exclude others which are considered as irrelevant. The AIDS epidemic offers an excellent case for studying these strategic moments of problem definition and consensus building which shape public policies from their very beginning.

International comparison is of particular interest here, because every country faces a similar problem. But as no legitimate knowledge pre-existed to interpret the new epidemic when it occurred and the threat it might represent to society, problem definition and policy construction largely depended on the characteristics of national policy systems, institutional networks and decision making processes in health policies.[1] France has a higher number of AIDS cases than any other European country (except Switzerland which shows a higher level of cases per inhabitants) but France took longer than Britain to formulate public policy. Figures for 1987 (the turning period for public policies in most countries) as well as recent data, illustrate the discrepancy between the policy process and the concrete reality of the epidemic (see table). As in most countries, the geographical spread of the epidemic in France was unequal. As in Britain (although to a lesser extent) it is concentrated in two regions. From the 13,145 cases

This article publishes first results of an ongoing research project, funded by the Agence Nationale de Recherches sur le Sida (ANRS), France.

	31 December 1987		31 December 1990	
	Total number of declared cases	Per one million inhabitants	Total number of declared cases	Per one million inhabitants
France	3,073	55	13,145	234
West Germany	1,669	27	5,612	71
Italy	1,411	25	8,227	143
UK	1,227	22	4,098	71

Source: World Health Organisation, European AIDS Centre, Paris.

declared at the end of 1990, 52% were located in the Parisian area (Ile de France) and 14% in the Marseille area (Provence-Alpes-Côte d'Azur).

Important national differences exist on all major levels that determine public health policies. They have to be taken into account when analysing national policies against the AIDS epidemic:

the organisation of health care and the social security system;
the type of relationships between public and private institutions in sectors of medical and social care, and of scientific research;
the social status, degree of organisation and capacity for collective action of the groups concerned: homosexuals, haemophiliacs, doctors, researchers, moral authorities, health and social administrations;
the relationship between medical research, the pharmaceutical industry and clinicians;
the national issues raised by AIDS in terms of economic, ethical and symbolic issues.

French AIDS policies were marked by special characteristics which can be summarised under five provisional points:

1. Defining a public policy on such a new and unexpected issue as AIDS was disturbed, occasionally delayed, by electoral uncertainty which weakened the capacity for consensus of French society and the legitimacy of public intervention. The strong criticisms of the 'political class' during the 80s illustrate this weakness.
2. The characteristics of the French policy system, especially of decision making in health and social sectors, made the AIDS issue dependent on political decisions. As this level was weakened, policy decisions depended entirely on scientific legitimacy but here, too, consensus was lacking during the first years of AIDS because of internal differences within the scientific community. Since health policies in France depend to a great extent on professional and scientific expertise, the twofold lack was crucial and explains certain hesitations and delays in public action.

3. New actors and 'owners' of possible policies had first to emerge. It was a long process because they could only emerge on the periphery of established groups. Internal debates had to be overcome and alliances across different fields built up between researchers, homosexuals and public officials, in order to establish and reinforce authority.
4. The new set of norms the first AIDS experts proposed proved acceptable because they fitted into the previous norms of health and social policies more easily than other alternatives. Neither the traditional message of the Catholic church nor the demands for social segregation put forward by the National Front had any influence on central policy adoption. On the contrary, the homosexuals' message of social solidarity, individual responsibility and the right to sexual liberty was consistent with the norms of social policies over the last thirty years (abortion and divorce were legitimised on the grounds of individual choice).
5. The government's role was to invent new administrative and technical modalities to integrate the new issues into existing legislation, medical systems and social negotiation. When the legitimacy of the political system was reinforced, the new policy was implemented with surprising speed, according to the well-proven model of a big 'national project'.

It is an open question, too early to be assessed, to what extent the innovations introduced through the AIDS issue will contribute to a modification of traditional patterns of health policies in France. Will the new model of public action strengthen the position of public health? Will it favour new relationships between hospital and ambulatory care? Between social action and medical care? Between private and public institutions? Will it contribute to enlarged social negotiation and interest representation in the health sector? To promote patients' representation and new ways of arbitration between professional, economic and social interests?

The context of French AIDS policy

Four general contextual issues have influenced the French case. Each represents a major level of policy formation and has to be regarded as an independent variable.

The general political situation

France experienced major political changes during the 80s. The 'decade of AIDS' coincided with unusually frequent elections, several changes of government and major electoral reforms. In the 1981 presidential and general elections, the socialists came into power for the first time for nearly fifty years. The following local (1983) and general elections (1986) gave the majority to the opposition and thus created an entirely new situation for the Fifth Republic, the so-called *cohabitation* between a liberal Prime Minister, from the Rassemblement pour la Rèpublique (RPR) Party, and a socialist President (1986–8). Traditional alliances also changed during the 80s. The Communist Party lost its influence, the conservative parties split whilst an extreme right movement, the Front National, gained considerable electoral influence, up to 30% in some regions, with slogans of insecurity, anti-immigration and national decline. As all other social issues during the last decade, AIDS became a battlefield for general political competition. Growing politicisation of national life led to criticism of what the press called the 'political class' and weakened its legitimacy.

Health administration and medicine

Health and social administrations occupy a rather weak position within the hierarchy of public administration. The different departments inside the Ministry of Health and Social Affairs are subject to divergent pressures. On the one hand, there is growing control by the Ministry of Finance, on the other hand, direct intervention from professional groups, especially an influential medical lobby. Reforms that would threaten either established frontiers between administrative and professional territories or the internal hierarchy of the medical profession are difficult to carry through.[2] They lead to absence of decision making, especially when the borders between what is regarded as being 'medical' and as being 'social' or the relationship between hospital care and ambulatory care are to be reconsidered.[3] Fighting the AIDS epidemic obviously interferes with these traditional boundaries.

The position of public health within the decision making process, and more generally within the health system, is particularly weak. The information system is mainly orientated towards statistics concerning the range and the cost of medical services. These priorities result from the cost coverage system which is organised for reimbursement on a fee per item basis. Epidemiology developed rather late in France and then merely for research purposes and not necessarily according to public health goals. With the historical decline of infectious disease, the position of infectious illness and of virology within medical research also became less important. Some indicators may illustrate this weakness. The discovery of the AIDS virus by a research team from the Pasteur Institute did not result from institutional mobilisation, but direct personal relationships with clinicians caring for the first French AIDS patients.[4] If press articles of well-informed daily newspapers like *Le Monde* may be considered as an indicator, the discovery of the virus early in 1983 was hardly noticed in France. It became of public interest only after the same discovery was announced by the Americans and when the vital interests of the French medical research and pharmaceutical industry were at stake.

The first medical term used in France was 'AIDS', the French equivalent 'SIDA' coming into use only several months later, at the end of 1983.[5] This indicates the degree of dependence of European science and public concern on American standards. This external dependence might be linked with the weak internal position of particular fields of medical research and public health. But at the same time, the French discovery and the existence of a well-established institution, the Pasteur Institute, has made AIDS an issue of national interest for France, in terms of the international prestige of French research and the potential economic benefits. Such vital issues, however, are far beyond the competence of the French health policy sector.

The public policy process

Health and more generally social policies in France are traditionally conducted by an alliance of certain segments of the politico-administrative system and certain segments of professional groups. These rather closed systems tend to reproduce existing conditions and to oppose reforms. Innovations emerge either in exceptional circumstances, like the 1958 hospital reform and the 1960 medical agreement,[6] or as a result of initiatives from high public officials acting in connection with private associations they promote as external pressure groups. National policies in favour of the elderly and of the handicapped during the 60s and 70s are examples of this model of change.[7] In industry and technology, innovation often proceeds in the form of 'big national projects' promoted by the state. The electrification of France, the nuclear power programme, ambitious projects like Concorde and the TGV high speed train are examples of changes promoted as national priorities.[8] When the AIDS problem arrived, there was no professional or administrative constituency to take it up and provide sufficient legitimacy for a big national project. Opinion polls, however, showed that the fear of contamination was a growing preoccupation among the public during the early years of AIDS.

Social negotiation and interest representation in the health sector

As a result of the situation described above, or as one of its reasons, there is little public mobilisation for health issues in France. They occupy very little space in the programmes of political parties or of trade unions and there are few debates on health issues in Parliament. Several movements of 'health service users' emerged during the 70s but they were closely linked with militant doctors who opposed the dominating structures of public hospitals and private medicine. These movements disappeared along with the militancy of the professionals.

Unlike in Great Britain where the National Health Service is under direct state authority and therefore a 'political ' issue, the French social security system is managed by social partners, i.e. the trade unions and employers' unions, but without competence over the organisation of services and structural evolution which remain in the hands of the government. Unlike in Germany where health policies have always been considered as part of general economic and social policies, health policies in France are considered as medical issues, concerning doctors. Health insurance merely operates as a payment office, a function which does not give rise to major public mobilisation.

The French homosexual community was initially not prepared to take up the AIDS problem which caused great uncertainty about the future of the community, fear of renewed marginalisation and internal conflict about the basis on which to organise the struggle against the epidemic and its consequences. The national organisation of haemophiliacs was not able to break its traditional dependence on the blood transfusion centres through which patients were contaminated. These centres provide daily medical care and emergency services to haemophiliac patients. The latter prefer the traditional service structures they have always known to other hospital services with changing staff and priorities. In fact, the blood transfusion centres acted as representatives of the haemophiliac patients and as their mediator in all public relations. Feeling deeply betrayed and isolated, the National Association of Haemophiliacs has started only now to integrate into its self-perception a dimension of political mobilisation and autonomy from medical guardianship. The AIDS epidemic struck France in a sort of social and administrative vacuum and at a period where general political issues made decision making a particularly difficult exercise.

The policy process

Three phases in the policy construction process can be distinguished. Until 1984–5, established elites ignored the emerging problem whilst newcomers mobilised problem perception and provided technical tools. In spite of the conflicts that then arose over the use of blood tests, major public policy lines were established between 1985 and 1988, but implementation of the AIDS programme suffered from the difficult political context of the 'cohabitation' period. After the re-election of President Mitterrand in 1988, the reinforced social consensus favoured rapid implementation of the policy which was then conducted as a national priority.

1981–3: problem emergence and definition

The first news about AIDS reached France in June 1981 when the Morbidity and Mortality Weekly Report published details of the first cases. At the same time, a

Parisian hospital doctor met a case showing similar symptoms. As other cases soon followed, he set up an informal group to observe the new illness and discuss scientific literature. The group was soon joined by a psychiatrist, an immunologist, two officials from the Ministry of Health and an epidemiologist. The group obtained some formal status, attached to the Ministry's General Department of Health who agreed, in early 1982, to study leave for the epidemiologist. It was through the initiative of this first working group on AIDS, convinced of the gravity of the problem, that infected cells from a Parisian patient were provided to researchers from the Pasteur Institute who succeeded in isolating the HI-virus early in 1983. After the discovery, with the arrival of the virologists, the first expert group evolved in two distinct directions: on the one hand, an epidemiological surveillance system was set up as part of the General Department of Health; and, on the other hand, an association ('ARSIDA') aiming to develop research on AIDS and to obtain funding was set up under the leadership of the Pasteur group.

The first press articles on what they still called 'a mysterious epidemic in the United States' were published in January 1982, reporting on medical questions without mentioning the first French expert group. There was little mention in the general press about the isolation of the virus and the first blood test for which a patent demand was submitted in September in Europe and for the United States in December 1983. These events were reported only later, from 1984 onwards, when the 'scientific war' brought French and American institutions into open opposition.

The 'Association of gay doctors', which had been founded just before AIDS was recognised in France[9] in order to meet growing concern about specific health problems in the community, especially syphilis and hepatitis B, was already confronted with the first patients presenting the symptoms of AIDS. The association was also asked by the first expert group to collect and spread information within the gay community and the medical profession. It preferred, however, a discreet attitude in order to preserve the gay community from a public backlash. This reluctant attitude of gay doctors began to change during 1984 and the first specifically AIDS-orientated associations started operating within the gay community.

The first public intervention began in the summer of 1983. In June and August, the General Department of Health issued three 'recommendations'. These reminded health workers of hygiene and security measures; suggested to the blood transfusion centres (which organise all blood donation in France) that they 'avoid risk groups' (homosexuals, intravenous drug users, persons of African and Caribbean origin and their partners); established a surveillance system, in order to know whether the first French cases presaged epidemiological developments such as those in the States and eventually to prepare an adequate intervention structure. At the same time, the first funds were made available for research, from the National Institute for Health and Medical Research, the Ministry of Research and Technology and the Foundation for Medical Research. Allocation of these funds led to conflict between leading medical professors, especially from the fields of cancer and immunology, and the existing expert group from the General Department of Health (this 'French working group on AIDS' was chosen as the World Health Organisation (WHO) group for Europe in October 1983 and the European WHO centre for AIDS was set up in Paris in November 1984). The French scientific community developed at that time two hypotheses concerning the nature of AIDS:

the majority of cancer, immunology and virology specialists considered that AIDS was some normal infection that would only strike persons already weakened from other infections or disease and therefore, it would not be easily transmitted;

a minority of less known specialists, among them a number of virologists and the Pasteur research team led by Professor Montagnier, declared that AIDS was an infectious disease caused by an active viral agent.

During the autumn and winter of 1983–4, each of these different scientific disciplines organised its own working sessions on AIDS, with international participation in Paris. Commenting on these debates to the press a year later, Professor J. P. Levy, now the President of the National Research Agency for AIDS (ANRS), recalled the history of medical science and the relationship between cancer, retro-viruses and the immune system which had been known since the beginning of the century.[10] This was a call for interdisciplinary collaboration.

By the end of 1983, more than 100 cases of AIDS were already diagnosed in France, most of them in the Parisian area with an overwhelming majority of homosexual men, half of whom had travelled to the States, Haïti or central Africa. One haemophiliac case was already known but no intravenous drug users at that stage. The first year of AIDS policies in France was characterised by a lack of consensus within the scientific community. Health authorities were thus unable to take any further action.

1984–5: policy emergence

The Pasteur blood test was developed experimentally during 1984 and large-scale production started in the spring of 1985. The provision of a technical tool helped to define scientific consensus over the nature of the disease and indicated specific policies to be followed. Implementation, however, depended on national priorities, international legitimacy and initiatives from civil society. These issues and important controversies between policy deciders marked the period of 1984–5.

The most important private association in the AIDS field, called 'AIDES',[11] emerged at the end of 1984 and started operating in early 1985. It aimed to promote solidarity with patients, to spread information and to establish preventive measures both against the epidemic and against the risk of group stigmatisation. This mobilisation coincided with growing media interest. Well-known French intellectuals and artists were among the first AIDS victims. Famous patients from abroad began to arrive in French hospitals to seek the best available treatment (Rock Hudson died in Paris in 1985). The World Health Organisation chose the French epidemiological survey group to set up the WHO Centre for Europe. However, the major event which mobilised French authorities and the press was the announcement by the American Secretary of State for Health of the discovery of the virus in the US. A patent was rapidly granted to the American team; the earlier French application remained unanswered. Tension with the American authorities grew into an open legal battle during 1985. This focused on free access for the French test to the American market and to other continents (mainly to Africa where branches of the Pasteur Institute are traditionally well established). It was in this climate of intense international competition that the first compulsory measures were decided upon in the summer of 1985. At the same time the Minister of Social Affairs announced to the press an 'important AIDS treatment success', with cyclosporine after experimentation on a very limited number of patients for only one week, a declaration immediately criticised by the entire scientific community and by the Secretary of State for Health. This rather unusual incident illustrated the central preoccupation of the French government. It was concerned to preserve national interests, an economic priority which caused latent conflicts between government departments, the first AIDS experts and other health policy constituencies, mainly the blood transfusion establishment.

The first tests, available in limited quantities since early 1984, were used to study HIV prevalence in the population of haemophiliacs and in blood donation. Nearly half of the haemophiliacs tested were found HIV positive. As early as March 1984 numbers were concentrated in the Paris region – these corresponded to the high local prevalence of blood donation. They were also particularly high in the group of patients regularly using concentrated blood products. Since no immediate alternative seemed to exist, these alarming results were not communicated to the public, nor to the patients and their associations. The AIDS experts insisted on a series of measures which had to be taken immediately. There had to be systematic testing of all blood donations with information and medical advice to be given to all donors who proved positive; provision of voluntary and free of charge test facilities for everyone; limitation of the prescription of blood products and the provision of heat-treated blood products. All these measures marked a profound change in the traditional ethical basis of the blood institutions. They brought radical change to an organisation which had previously been based on concepts of voluntary donation and of a system of provision which was considered safe because it was national, voluntary and non-commercial in origin. The heating process also necessitated an important technical transformation of all blood donation centres. The safety of the blood supply was based on systematic screening of all donated blood for various viruses, especially hepatitis B. This was thought to make heat treatment unnecessary. The blood transfusion and related industries were publicly funded, so all centres had to be equipped at the same time, in order to provide all patients with equally safe products. This meant that increased imports, withdrawal from the market of all untreated French products and the destruction of stocks would be necessary if the recommendations put forward by the AIDS experts were to be put into practice. These public health measures were in opposition to other important policy goals the government was pursuing. If the Pasteur test was to get a good share of the market, then it had to be competitive before the establishment of systematic screening of blood donation and the development of voluntary test facilities. All these measures also meant increases in health expenditure, already subject to severe restriction. Last but not least, differences of opinion existed among the blood and haemophilia specialists on risk appreciation and the means to reduce the risk. In order not to discourage blood donation, the blood centres had been reluctant to select and refuse risk groups on the lines recommended by the Ministry of Health in June 1983. Haemophilia patients and their doctors also resisted any moves which might limit access to the new coagulation treatments which had been hailed as major medical progress, increasing the patient's autonomy and security.

In this context, a lack of expert consensus, an absence of patient protest, decision making proved difficult and was delayed for a few months. The government followed AIDS experts in areas where consensus existed with the haemophiliac community, for example compulsory blood screening and voluntary test facilities. It followed the haemophiliac and blood transfusion establishment in not limiting the distribution of unheated blood products, although these were already known as unsafe, until the stocks were used and provision of heat-treated products had been guaranteed both by imported heat-treated material and by the production of such material in France. The question of responsibility for these 'unacceptable delays' has now become the subject of intense public scandal, with important legal consequences. Decisions were taken by the Prime Minister in June 1985. The Order (*arrêté*) of 23 July 1985 introduced compulsory testing of all blood donations, applicable from 1 August 1985. This measure was extended to organ donors in 1987. The question of whether donors should be informed or not of positive results remained open until the National Committee on Ethics decided that they should be. The circular of 20 October 1985 confirmed this duty to inform and issued guidelines on how people should be informed of their seropositivity. This was always to be during a personal consultation with a doctor. A second Order of 23 July fixed prices for heat-treated blood products and cancelled health insurance reimbursements for non-heat-treated products, but only from 1 October. This specific delay, between the decision and its application, was the starting point for mobilisation around the French 'blood scandal'.

There were important developments in society during this period of difficult public choice. Unlike the United States of America, the homosexual community was not organised as such in France. Special group identities are not recognised and sexual behaviour is not considered as a matter of public concern. The gay community existed through its specialist press and meeting places. Some gay militancy had emerged in the early 80s when an obsolete discrimination law was abolished, but the impact of AIDS put the movement back to its infancy. AIDS militancy grew from the personal initiative taken by Daniel Defert, the intimate friend of Michel Foucault. He founded the 'AIDES' association with the aim of representing the interests of all AIDS victims, irrespective of whether they were homosexuals or not, acute patients or sero-positive people, and to build alliances with laymen and specialists from all fields of relevant knowledge against the risk of excessive medical or state power over the AIDS issue.[12] His strategy relied on Foucault's philosophy of 'micro-powers' and a previous experience as an extreme left militant. The leader of the association, although gay himself, considered the homosexual community as too marginal to cope with the AIDS problem and its social identity, only based on sexual liberty, as too fragile. His strategy encountered opposition in the gay community, an opposition which lost support, however, as blood tests and the first medical treatment became available. AIDES started operating in early 1985 and focused initially on improving the conditions around acute medical care in hospitals. The association rapidly became a pressure group urging voluntary, free test facilities and preventive measures, such as publicity for condoms and free sale of syringes. It became evident to the AIDES activists that despite Foucault's aim to keep the state out of sexual regulation, large-scale AIDS prevention and social solidarity needed state support. But the government was struggling through a difficult decision making process, as new general elections approached. This was the origin of the argument that France was 'late' in developing policies on AIDS.

In the autumn of 1985, two months after the introduction of compulsory testing of blood donations, the number of contaminated donors was known. This was the equivalent of one per thousand donors, with important regional differences. In several regions not a single positive person was detected. There was a strong concentration in urban areas, especially in Paris and Marseille. Statistical extrapolation for the whole population suggested a total of 50,000 infected people in France. This figure became subject to passionate debate. Was this a minimum hypothesis because the risk groups had already been filtered out by the preliminary questionnaires filled in before giving blood? Or, on the contrary, was the figure an overestimation? AIDS experts argued that risk groups continued to use the blood collection centres, in particular to obtain AIDS tests which were not yet easily available outside hospitals. The idea of creating special centres for AIDS information and anonymous HIV testing took shape during these debates.

1986–mid-1988: public intervention

Major AIDS legislation was passed in a most difficult period of general politicisation and in a situation which the French political system had not experienced before. The Fifth Republic had previously always had a President and a government coming from the same political party. Between the 1986 general election and the 1988 presidential election, the socialist President had to deal with a conservative government, whilst the entire political system was under growing electoral pressure from the extreme right-wing Front National.

The new Chirac government was initially set up without any particular person in charge of health, an omission that illustrates the low position of public health in the hierarchy of French administration. After protests from the medical profession, Michelle Barzach (unknown till then) was appointed as Minister of Health. It was her task to legislate the prevention policy formulated by the first AIDS expert group. As she took office, the AIDS group attached to the General Department of Health passed her an internal report outlining the way they saw the problem and the measures which should be taken.[13] The French position on the scientific front was strengthened by the isolation of the second AIDS virus in the Pasteur Institute in February 1986 and by growing consensus in the international scientific community. An international commission proposed to call the virus 'HIV', as a compromise between the American and the French research teams and the Second International Conference on AIDS was held in Paris in June 1986. It provided an excellent platform for the new Minister of Health to publicise her policy.

Two significant measures were put into practice almost immediately. AIDS was added to the list of compulsorily notifiable diseases (decree of 10 June 1986); a circular on 3 September 1986 opposed restrictions on patients with AIDS travelling by air. This was the first step towards preserving freedom of international travel and cutting down demands for segregationist policies. In November, Madame Barzach announced her programme. It had three major strands: the creation of a research centre on AIDS; the promotion of international collaboration; and the declaration of AIDS as a 'national cause' for 1987. The Health Minister appointed a medical professor[14] as 'Mr. AIDS', a general co-ordinator for research and medical options; and a special research council was set up to supervise the distribution of funds. The effectiveness of these structures, however, remained uncertain. They did not gain sufficient support either from the medical elite or from the public research institutions. International collaboration aimed essentially at resolving the French/American conflict. A high level meeting between Reagan and Chirac, followed by meetings at the Health Minister level, aimed at a compromise, one much criticised by members of the French research teams. They considered the financial compromise as 'capitulation'; and also expressed concerns about the equitable distribution of the French section of benefits between the different French institutions covered by the agreement. For the first time large-scale public funding was allocated to AIDS in 1987. There was 110 million francs for research projects on treatment and vaccine (for a two-year period, 1987 and 1988); 40 million francs of extra funding to Parisian hospitals; and a subsidy of half a million to the 'AIDES' association to promote information and prevention campaigns. The 1988 budget made a special allowance of 760 million francs to the national health insurance fund which henceforth had to reimburse the cost of all voluntary blood tests, according to the ordinary procedures for medical services.

Public prevention policies were based on three premises. First, public information was disseminated through television campaigns and through school-based education. The first French television campaigns were rather careful and indirect, far less explicit than in northern European countries. In schools, the campaigns remained under the supervision of the Ministry of Education. Here, AIDS was not to be treated as a specific issue but integrated within more general subjects such as the prevention of drug use or sexually transmitted diseases, as part of general sexual education. Promotion of safer individual behaviour was the second strand of the prevention policy. The emphasis on condom use made it necessary to abolish a 1967 law prohibiting the advertising of contraceptives, including condoms (law of 21 January 1987). The open sale of syringes was allowed by Order of 13 May 1987, despite some initial protest from the chemists. These two measures naturally raised conservative criticism, in particular from the National Front, the only political organisation to mount an anti-AIDS crusade. Thirdly, new service structures were provided to offer easy access to information, care and HIV blood testing. By February 1987, eleven centres for ambulatory care and information were in service and two centres for anonymous and free of charge HIV testing. The latter were rapidly developed to form a network covering the country, according to the law of 30 July 1987 which required at least one centre in each administrative district (*département*). By June 1988, 109 testing centres were in operation and 118 exist currently.

The controversial issues of compulsory screening for foreigners entering the country, pregnant women and pre-marital medical examination arose at this time. These issues appeared under various guises, for example the compatibility of seropositivity with certain professional occupations and the general screening of the population or of certain groups considered as particularly at risk. Demands came up for the systematic screening of pilots, train and road transport conductors, supported by some medical professors arguing on the grounds of 'nervous risks'. The state set the example in the field of occupational rights. Although entry into public service jobs is normally subject to precise health conditions (excluding for instance persons with tuberculosis), HIV screening or questions about lifestyle were banned from selection procedures. The first concrete case concerned a young teacher with pre-AIDS symptoms. He was supported by his trade union, colleagues and the parents' association, probably with some guidance from official levels,[15] as his case constituted a precedent. The case was dealt with through the normal procedures of examining the teacher's aptitude for the particular job as well as by the usual medical commission. Henceforth it was established that AIDS specialists have a role on these commissions when an HIV positive case is under examination. A leading organisation for cancer research urged general population screening but the Health Minister and leaders of her party (RPR) refused any debate on this subject. Demands for compulsory screening or for segregation were localised. They arose from defined professional groups defending specific corporatist interests and from a single extremist party. Official policy focused on voluntary testing, public information and personal responsibility.

The law of 30 July 1987 constituted an indirect but quite definite answer to these controversies. The first article ordered that 'the definition of policy against AIDS is the responsibility of the state', to avoid divergent local policies linked with electoral issues. Consequently, and for the same reason, AIDS was not added to the list of 'sexually transmitted diseases' which are the responsibility of local government, although information campaigns often treat AIDS within the chapter of sexually transmitted diseases (STDs) in order to prevent particularisation and dramatisation of the subject and treat it as part of more general issues. The second article established the network of centres for voluntary, anonymous and free blood testing. Madame Barzach's efforts to implement an active prevention policy gave rise to social debates with political and ethical issues. Four discussion centres can be distinguished.

1. The main debate was of a partisan nature. The conservative parties in government had to clarify their position against the extreme right-wing National Front, a potential political ally, which was demanding compulsory screening of the population and isolation of the seropositive and ill persons in 'sidatoriums'. The National Front linked its AIDS strategy with its general ideology in favour of traditional morality and nationalism, based on opposition to abortion and immigration and a rhetoric of national decline. In May 1987, the RPR ministers officially rejected all arguments by the Front National on AIDS and on immigration. Henceforth, a firm consensus

existed within the political elite, from the right as well as the left, against restrictive and segregationist AIDS policies.

2. Activist organisations in the AIDS area based their militancy on a respect for human rights. They aimed to preserve AIDS victims from social and medical discrimination and to protect their access to work, housing, insurance cover and normal human contact. In October 1987, the AIDES association and a well-established humanitarian organisation, Médecins du monde, published together a 'Bill of rights for AIDS victims', which aimed to provide guidelines for the ethical and social dimensions of AIDS policies.
3. The French Catholic church was confronted with the very traditional position of the Vatican and growing internal criticism. The French bishops supported the Vatican position on solidarity with the sick but remained distant from the Pope's demand for a new sexual morality. They declared officially that 'AIDS was not a divine punishment', a statement aimed to establish a clear distinction between the official church and a wing of religious traditionalists that had split from the official Roman Catholic church and maintained links with the National Front. The internal debate progressively shrunk to focus finally on condoms which it was argued could not be considered as 'the only solution to the AIDS problem'.
4. The last area of debate, confidential at that time, confined to expert circles and ministerial departments, concerned haemophiliacs and blood transfusion. Some blood centres admitted that unsafe products might have been distributed and suggested autologous transfusion for non-urgent operations. When demands for compensation for victims were discreetly put forward by the president of the National Association of Haemophiliacs (a top diplomat), the official response was firmly to refuse any negotiation. When the president died of AIDS, in July 1988, there was a split in the association. A splinter group engaged in open protest, burning the car of the Director of the National Centre of Blood Transfusion.

The period from 1986 to mid-1988 was marked by social debates over the question of how to use the technical tools now available (blood tests) and by conflict over the influence groups promoting different policies should have in the decision process. Although consensus existed within the political elite over the principles underlying AIDS policies, this period was characterised by a need for legitimacy from outside, by reference to international norms. Policy discussion on the question of screening foreigners entering the country was based on European EC and WHO recommendations, Madame Barzach used international platforms and frequent press conferences to publicise her policy. President Mitterrand, much in favour of ethical councils acting as independent expert advisory bodies for government action in new medical and scientific issues, put forward his proposal for an international ethical council on AIDS at the meeting of the seven industrialised countries in Venice in June 1987.

From mid-1988 onwards: a national priority

Although major regulation was achieved and essential principles clearly established during her period in office, Madame Barzach did not have the means fully to implement the policy. The Chirac government was committed to reduction of public expenditure; the next Presidential election was due in May 1988. The re-election of President Mitterrand strengthened consensus within French society and the legitimacy of public intervention. AIDS policies were implemented in these more favourable circumstances. One surprising incident, however, marked the change. The newly appointed Minister of Health, a popular medical professor known for his outstanding opinions, had to resign after just one week in office. He had announced without consultation a number of innovations, including compulsory HIV screening for all pregnant women and candidates for operations. Two months later, after having taken advice from all ethical institutions in the medical field, the government recommended that HIV tests should be 'systematically offered' to all pregnant women. They remained free to refuse the test.

The newly appointed Minister of Health (Claude Evin) asked a well-known public health specialist to report on the AIDS situation and propose policies to deal with it. In November 1988, the 'Got Report',[16] named after the author, confirmed the previous policy principles of public information: strict prohibition of compulsory screening, the emphasis on voluntary testing and condom use. He insisted on the previous choice of treating AIDS and related problems with reference to existing rules and avoiding specific AIDS regulations or structures. He castigated the ineffective French official infrastructure dealing with AIDS (three people with part-time responsibility and a single small office were the total ministerial input, and this for a problem officially termed a 'national cause'). He criticised the low research investment in a case where the country could lose a predominant place in the international market. He proposed a strategy based on the model of big national projects: the AIDS issue should move from the level of the Health Ministry to an interministerial approach. The major recommendations of the report may be summarised as follows:

The creation of a national research agency to promote and co-ordinate all AIDS linked research. Research budgets should be tripled immediately from 50 million francs in 1988 to 150 million in 1989. This national structure would define and orient research policies, and replace the modest research council previously established by the Minister of Health and whose function was in fact limited to arbitration in fund allocation between the competing medical constituencies.

The creation of a national council on ethical questions related to AIDS, consisting of independent scientists, academics and intellectuals from all fields of social and philosophical knowledge. The ethical council should report directly to the Prime Minister. Its members should be appointed by high state authority to advise the government 'which should not be left alone to deal with the AIDS situation' (Got, p. 125).

Important financial support for information and prevention campaigns which should be directly targeted towards condom use. Budgets should quadruple immediately from 31 million francs in 1988 to 120 million francs in 1989. The task should be carried out by the existing Committee of Health Education, a public body reporting to the Ministry of Health; its standing and authority should be reinforced; it should therefore have a scientific council of unquestionable authority.

Special funding for the public hospitals in Paris which dealt with most French AIDS patients. Additional funding for hospitalisation of AIDS patients should be extended from 1,000 million francs in 1987–8 to 2,750 million francs in 1990 with an additional 36 million francs for community care facilities.

Promotion of social solidarity with AIDS victims, in every field from medical care to human rights.

Creation of an 'interministerial governmental action committee on AIDS'. This committee should be attached to the Health Ministry but report directly to the Prime Minister and be directed by a high state official, trained at the famous ENA School[17] in order to exert a credible authority over AIDS issues in all ministries. The committee should be responsible for international relationships and for providing society and public administration with exact information on AIDS, to prevent the diffusion of misunderstood scientific debates and the political abuse of ignorance. The previous solution of a 'Mister AIDS' nominated only by the Health Minister was obviously less than the type of the mission at which Got was aiming.

The Got Report recommended that future AIDS problems should always form part of general frameworks for similar problems. Controversial issues were discussed in the light of this guideline. The report argued that it was difficult for insurance companies not to demand medical tests when the applicants were free to take them, because the entire insurance business was based on the logic of 'probability'. The insurance problem for AIDS victims should be considered with reference to insuring other chronic diseases. The problem of penalising deliberate transmission of the virus should not be dealt with through the existing legal categories (injury, poisoning, attempt to hurt or to kill) but required a new more general category, centred on the idea of 'risky behaviour dangerous to the health of others' which would include dangerous driving, pollution and adding dangerous ingredients to food. The haemophiliacs' demand for compensation, he argued, was difficult to meet as a specific issue since no such compensation exists for other illnesses contracted through medical treatment. To limit the transmission of the virus in prisons, the report suggested the improvement of general living conditions and medical care in prisons and the provision of facilities for conjugal visits. For drug addicts, the report proposed an official investigation of the 'Patriarch' organisation, a private international organisation treating drug users and confronted with a high concentration of HIV positive patients. Its services should be evaluated in order to assess how far they conformed to French legislation and the possibility that they could collaborate with public services for drug users.

The government followed most of the recommendations of the Got Report and implemented them with surprising rapidity, as far as research, funding and promotion of condom use were concerned. The Minister of Health announced his 'National Plan against AIDS' to the press in early November 1988, stating that 'AIDS is no more a group specific illness but concerns everyone.' The first television campaign promoting condom use started the same month. In December, the first working group on AIDS was set up in Parliament. The National Agency for Research on AIDS was fully operational in February 1989. It is linked to the Ministry of Research and INSERM, the national institute for medical research. An ethical advisory body was set up by Order of 8 February 1989, as the 'National Council on AIDS', and its president – an anthropologist – was appointed directly by the President of the Republic. Its major work so far has been on the ethics of information and on insurance.

On two major points, the government did not follow the Got Report. First, a specialised 'French Agency for AIDS Prevention' was set up in January 1989, to elaborate and pilot mass campaigns and specific prevention action, in collaboration with the newly created AIDS Division in the Ministry's General Department of Health and the private AIDES association acting as a service provider. Unlike the research agency, it took a full year to install and staff the prevention agency, which has private status despite its direct attachment to the Health Minister. This unusual compromise may allow the government not to appear directly involved. Secondly, the 'Governmental Action Committee on AIDS', a key element of the infrastructure proposed by Got, was not set up. This leaves decisions in the hands of the Prime Minister and the President of the Republic.

This national AIDS policy was based on a broad consensus in French society, from researchers as well as from political actors. The National Front lost much of its support over AIDS. The condom campaigns only mobilised consumer associations who found that a third of condoms tested were not safe (France does not produce condoms but has to import them). The government reacted immediately by imposing strict French technical standards and withdrew five brands from the market. The Protestant church officially approved publicity for condoms in November 1988 and the Catholic church finally declared that there was no official line on these subjects. Bishops were free to adopt the position they judged reasonable according to their own conscience and the needs of those they had to care for.

Policy content and implementation

Two contradictory characteristics mark French public policy. On the one hand, it is a guiding principle that special structures for AIDS patients should not be created, the epidemic should be treated within the existing channels of social administration and health services, in order to avoid the risk of social stigmatisation through technical specialisation. On the other hand, specialised agencies were created and AIDS experts on the national level conduct the policy outside the ordinary decision making processes. Two specialised AIDS divisions function within the Ministry, one in the General Department of Health and the second, less important, within the Department of Hospital Management. Each is established separately from normal bureaucratic structures and directly attached to the Director of the Departments. There is a national expert community, composed of executives of the National Agency for Research on AIDS, the executives of the two special AIDS divisions of the Ministry of Health, the president of the Ethical Council on AIDS and the director of the National Agency of Campaigns against AIDS. These structures (which now have a permanent staff of more than fifty persons) represent an important innovation in French administration. The AIDS issue was not only taken out of the ordinary hierarchy of health and research administration, but for the first time in the history of the Health Ministry, organisation proceeds *according to illness*, with special horizontal units treating the whole range of problems connected with that one illness. On the contrary, medical care for patients with AIDS and most prevention activities are integrated into the normal system of services and the social security coverage. The compulsory notification of AIDS diagnoses, like all other AIDS relevant information, are collected and analysed by the AIDS division operating in the General Department of Health which deals with declarations of all other infectious diseases.

AIDS was simply added to the list of some thirty illnesses which, under the health insurance, are reimbursed up to 100% of expenses (Order, 31 December 1986). Patients with AIDS related complex (ARC) have approximately 70–80% of expenses reimbursed. Hospitals are advised to treat AIDS patients in their normal infectious diseases and other services. Special funding was provided to extend the capacity of home care units, but the home care associations have not always been able to define their special needs as quickly as the government expected. All doctors can prescribe HIV tests. Since 1986, they are paid for and reimbursed like any other medical examinations. Free and anonymous HIV tests are provided within local prevention centres, in vaccine centres or in the new units set up as part of local public health services. According to the AIDES association, which should be the most critical observer, 'there is no problem for medical care in France . . . and the line of social integration and solidarity was perfectly maintained by public authority' (interview). All medical and dental services are expected to accept seropositive patients. Respect for the normal rules of hygiene is considered an ordinary professional responsibility which should offer sufficient security.

The necessity of treating growing numbers of AIDS patients has led to the development of community care and to limitations on the traditional liberty of doctors to prescribe the medicine they see fit. By far the major part of AIDS treatment (80%) occurs in public hospitals, leaving only 20% to the private sector. The day-hospital has become the central point in the organisation of AIDS care and 'hospitalisation at home' an important part of the care structures. The most prescribed medicine is AZT, which is prescribed twice as often as any other form of Retrovir. According to a recent study,[18] at the stage of acute AIDS there is little difference in access to medical care between social groups, for example the homosexuals and intravenous drug (IVD) addicts. By comparison, social inequality still continues in the field of pre-AIDS care for seropositive persons: drug addicts have far less access to care than homosexuals. Only hospital doctors can prescribe AZT, independent practitioners can only renew the prescription.[19] National training programmes on AIDS for health and social workers are conducted by the AIDS unit of the General Department for Health, with the aim of providing professional advice and psychological support to clients everywhere when AIDS related problems arise.

The Ministry now wants to limit the number of HIV tests prescribed by general practitioners and to favour the role of the anonymous testing centres where the percentage of positive results is higher. A more focused strategy for HIV testing and prevention seems about to emerge. Up till now and against all epidemiological evidence, AIDS has been presented as concerning 'everyone' in the same way. Prevention policy was the same for the whole country. But France is clearly confronted with three different epidemics: AIDS is concentrated in the Parisian area dominated by homosexual transmission; in the south-eastern area (Marseille–Nice) dominated by IVD transmission; and the Caribbean overseas territories with heterosexual transmission patterns. The dilemma of how to warn the public of contamination risks without stigmatising the groups known as risk carriers, was solved in France by disassociating AIDS from homosexuality. This choice was in line with the state's tradition of not intervening in matters of private lifestyle and of not recognising special group identities. It may be the explanation (rather than any sense of discretion about homosexuality or sexual matters) why French public campaigns did not use moral arguments in any way. The second feature of public policy was a determination to avoid spreading information not yet the subject of scientific and political consensus. Haemophiliacs, drug addicts and prisoners paid a heavy price in this consensus orientated policy. Decisions on prevention of contamination through blood products were left to the closed community of specialists on transfusion and haemophilia.[20] The state is now confronted with severe criticisms for not having faced up to its specific responsibilities. Apart from the free sale of syringes, AIDS strategies in the field of drug abuse and in prisons remained largely limited to prohibition of testing without consent.

In areas where norms of behaviour are part of a particular group identity, special action has to be taken in alliance with insiders. The National Agency for Campaigns against AIDS covers these types of areas, together with the special AIDS division of the Ministry and the private AIDES association. There are frequent problems with respect to their respective areas of competence and functions. The AIDES movement spread geographically throughout the country. Local associations, affiliated to the national federation, now exist in every large town. They offer a variety of services, according to local needs, ranging from the collection and diffusion of information inside and outside the risk groups and professions concerned with AIDS, telephone hotlines, legal advice, discussion groups, individual psychological and social support from volunteers in hospitals and at home, accompanying the dying[21] and initiatives to promote home care in order to preserve social links. AIDES perceives its role as that of a pilot movement proposing new public policies and representing the interests of AIDS concerned people. It played this role with remarkable success, shaping public opinion and developing social visibility around the epidemic. On the service level, however, AIDES depends entirely on project bound funding from public authorities which might limit its independence as a social actor.

During 1991 three important measures have further marked implementation. Article 187 of the penal code which outlaws discrimination on the basis of nationality, race, sex and religion was extended to cover health handicaps. It is now illegal to exclude people from employment, public places, public transport, housing, shops or restaurants, etc. The organisations representing patients or handicapped people can take offenders to court. France thus implemented the WHO recommendations on social rights for the sick. The second decision, taken jointly by the Health Minister and the Minister of Finance, concerns access to insurance for HIV positive people. Any questions related to lifestyle are henceforth prohibited in insurance questionnaires; demands for HIV tests are only allowed in conjunction with other medical examination and for policies paying over one million francs (the sum is subject to revision according to price indexes and the evolution of the epidemic). Seropositive applicants are entitled to insurance, via the category of ‘aggravated health risks’ with a higher subscription fee according to the rules already in use for people with other chronic disease. Penal sanctions can be applied to insurers who do not respect this law.

A third series of decisions since the autumn of 1991 concerns compensation for AIDS victims through blood transfusion or products. Unlike a first scheme set up in 1989–90, which provided only a fixed sum to help a defined group of haemophiliacs and excluded the idea of public responsibility, the new scheme explicitly recognises the public responsibility for solidarity with the victims. It includes all haemophiliacs and patients who were contaminated through transfusion. Compensation will be decided according to each individual case and with reference to common law principles. A special fund has been made available, funded jointly by the government and the national federation of insurance companies, managed by the latter who have been charged with negotiating compensation with individual victims, their families or lawyers. Acceptance of compensation does not exclude further legal action for specific medical negligence or mistakes. Reform of the entire blood transfusion system is under way to prevent similar accidents in the future.

Conclusions

The case of AIDS has often been presented as a major innovation in public policy. But was it really so new? French policy was initiated by scientific and professional experts linked with sections of the public administration, by a minority against established hierarchies. It followed one of the typical models of innovation in French public policy. The liberal approach, centred on voluntary testing and on medical confidentiality, was congruent with key principles of social policy established over the past few decades. Personal liberty and choice were continuously extended in fields of health care, abortion, contraception, divorce, age of retirement. It would have been difficult for the state to draw on authoritarian methods in the case of AIDS. All governments from the right and the left continued the same policy. This consistency might cause surprise in the case of France, better known for her passionate ideological debates than for her traditions of individual liberty and social solidarity. The National Front's attempt to oppose individual and public interests was not shared by society and ruled out by the political elite.

Was France late in promoting public policies against AIDS, as was often stated by activist groups? Precise international comparisons would be needed to answer this question. In certain fields, 'la grande Nation' was well ahead. France discovered the virus and was the first European country to set up a specific epidemiological surveillance system. French legislation was among the first to include systematic screening of blood donation and even the controversial distribution of untreated blood products was banned relatively early compared to other countries. Last but not least, France developed an extensive system of free and voluntary testing facilities. Delays occurred in two defined circumstances. On the one hand, each time political power changed hands on the national level, decision making or implementation was delayed. On the other hand, in fields traditionally dominated by closed professional groups (blood transfusion) or where a coherent anti-AIDS strategy would require joint action across existing professional and administrative borders (drug addicts, prisoners, extended home care), policies were not developed or were only partially implemented. Situated on the margins of medical and social action, these fields are traditionally difficult to co-ordinate. In its content as well as in its delays, AIDS policy seems to have followed the general logic of the French policy system.

However, the AIDS issue did introduce changes into the health system. The doctor's freedom to prescribe was limited. Home care facilities were developed and professional hierarchies and elite positions were challenged, under the pressure of newcomers and a social movement representing the patients' interests. The policy of social integration and solidarity with AIDS victims met the demands of the early AIDS militants, especially from the gay community, but these social demands had to be legitimated by science and by international references before a political consensus could emerge and enable the political system to establish them as policies. The AIDES movement filled a social vacuum. For the first time in France, social interests in the health sector were represented outside medical leadership. The haemophiliacs, reluctant to join a movement dominated by homosexuals, took several more years to break their traditional dependence on their doctors and caring institutions. Their isolation and silence were finally overcome with press support. Gay representatives obtained their place in the policy process at a certain price. They left behind group specific demands. The recognition of homosexual marriage or inheritance, promoted by gay groups linked with the Socialist Party did not reach the official discussion agenda. The AIDES leaders, on the contrary, built up their movement on a general philosophy of human rights and considered their campaigns for safer sexual behaviour and free access to syringes 'not only as a medical necessity but also as a way of integrating minority choices into socially accepted norms and values' (interview).

The French state reacted to the unexpected and quite special issue of AIDS by reinforcing the protection of private life and individual liberties. The administration was used to provide society with prevention facilities and useful statistical data to enable doctors, public health experts, trade unions and insurance to exercise their social function. New intellectual and administrative tools had to be elaborated and prove their efficiency in the special AIDS context; this meant delay. The 'normalising' process of the AIDS issue and these newly invented modalities illustrate the capacity of the welfare state to deal with unexpected social danger and new types of social risks.

NOTES

1 R. Klein and P. Day, 'Interpreting the unexpected: the case of AIDS policy making in Britain', *Journal of Public Policies*, 9, 3 (1989), 337–53.

2 B. Jobert and M. Steffen, 'Décisions et non-décisions en matière de politique de santé', *Contribution to the Congress of the Société Française de la Santé Publique*, Lyons, 16–17 May 1988 (Grenoble, 1988).

3 M. Steffen, 'Les politiques alternatives dans le domaine de la santé', Research report, 2 vols. (Grenoble, 1987).

4 M. Pollak, *Les Homosexuels et le sida; sociologie d'une épidémie* (Paris, 1988), 131.

5 C. Herzlich and J. Pierret, 'Le sida dans l'espace public', *Annales; Economie, société, civilisation*, 5 (1988), 1109–33.

6 H. Jamous, 'Professions ou systèmes auto-perpetués? Changements dans le système hospitalo-universitaire français', in *Rationalisation, mobilisation sociale et pouvoir*, Centre de Sociologie de l'Innovation (Paris, 1973), 5–55; H. Hatzfeld, *Le Grand Tournant de la médecine libérale* (Paris, 1963).

7 M. Steffen, 'Les politiques de la santé devant les alternatives', *Cahiers de Sociologie, de Démographie et d'Economie Médicales*, 28, 2 (1988), 163–78.

8 J. J. Salomon, *Le Gaullois, le cowboy et le samouraï; la politique française de la technologie* (Paris, 1986); J. Zysman, *L'Industrie française entre l'Etat et le marché* (Paris, 1982) (first English edition: *Political Strategies for Industrial Order* (Berkeley, 1977)).

9 The association had 240 members in 1988, according to Pollak, *Les Homosexuals et le sida*, 132.

10 *Le Monde*, 25 April 1985.

11 'Aides' means 'help' and 'support' in French (plural form).

12 Daniel Defert, 'Un nouveau reformateur social: le malade', *Communication Presented at the Vth International Conference on AIDS* (plenary session), Montreal, Canada, 6 June 1989.

13 'Rapport du groupe de travail sur le Sida' (Rappin Report), Direction Générale de la Santé, Ministère de la Santé, May 1986.

14 Alain Pompidou, the son of the famous ex-President.

15 'It was quite clear for us, that for public administration, there should not be any employment of screening, but we could not always speak up and say so. Generally, we arranged that some organisation, the trade unions of the public service or some other organisation would speak up for this. We also had contacts about it with the employers' unions' (interview, a member of the first AIDS expert group, Ministry of Health).

16 C. Got, *Rapport sur le sida* (Paris, 1989).

17 ENA (Ecole Nationale de l'Administration), the famous elite school which prepares candidates for high positions in the public administration and provides the state elite with a common culture.

18 Y. A. Flori, Y. Souteyrand and A. Triomphe, 'Les fillières de soins des patients VIH; les interrelations de médecine de ville et de médecine hospitalière', *Communication at the first French Seminar on Health Economics* (Dijon, 1990).

19 It was only in 1991 that doctors outside public hospitals were allowed to *renew* prescriptions for AZT. Young people who are not yet employed and therefore still covered by their parents' health insurance, but who do not wish their family to be

informed of their serological state can receive AZT treatment, free of charge, in Family Planning Centres, even if they are under the age of majority (eighteen years). This solution follows the model tried during the 70s for contraception.

[20] M. Lucas, 'Transfusion sanguine et Sida en 1985, chronologie des faits et des décisions pour ce qui concerne les hémophiles', *Report Presented to the Minister of Social Affairs and Integration and to the Minister Delegated to Health, Inspection Générales des Affaires Sociales* (Paris, 1991).

[21] Based on the French concept of *accompagner les mourants*; it means giving 'tender loving care', based on being present, listening, counselling and comforting.

Appendix

AIDS: the archive potential

JANET FOSTER

Archival holdings available for research of all kinds in the UK are among the most rich and extensive in the world. The wealth of these collections is shown in *British Archives* which contains details of the material held by more than 1,000 archive repositories, libraries, institutions and societies.[1] However, this is not exhaustive. There is more material to be discovered and records are being created continually.

The AIDS Social History Programme, based at the London School of Hygiene and Tropical Medicine and financed by Nuffield Provincial Hospitals Trust, has been engaged, since 1988, upon researching and writing the social history of AIDS in the UK. The work is concentrating on official policy making in the context of the various influences upon it from the statutory and voluntary sectors, the medical establishment and medical research.[2] An initial aim of the Programme was to establish an AIDS archive. However, before any decisions could be made about taking in material it was desirable to investigate the records being generated by those individuals and organisations involved in the AIDS arena. As an initial phase, a pilot survey was established, in January 1990, as a four-month project to identify the extent and scope of primary documentation for the history of AIDS in the UK.

Surveys of primary source material are not new. The Royal Commission on Historical Manuscripts was established in 1869 to locate and register archives throughout the country and its National Register of Archives now holds in excess of 31,000 lists and reports of papers available for the study of British history. In recent years surveys of primary documentation available for the historical study of specific subjects have become quite common. *Surveys of Historical Manuscripts in the United Kingdom* details almost 200 such surveys completed or in progress.[3] However, these have concentrated on historical material which is generally already to be found in archive repositories. The AIDS archive survey was completely different in being concerned with identifying potential archives, as they were being created.

Archivists have always been professionally interested in the full life-cycle of records – from creation through working life to destruction or selection for permanent preservation. But this has been a function of management within the record-producing body, concerned with regulating record-keeping whilst ensuring that the documents essential to recording the history of the organisation are identified and permanently kept as archives. However the AIDS archive survey took a subject approach to records management, locating and surveying records created by a variety of agencies, which would provide the source material for writing the history of an epidemic in progress. It is believed this is the first time an archivist has been directly involved in identifying primary source material for a specific topic of British contemporary history.

The aim of the pilot survey was to report on potential AIDS archive material in the UK by:

1. Locating collections of relevant personal papers
2. Locating archive material in organisations which are or were active in the AIDS arena
3. Identifying existing collections of material with relevance to the history of AIDS in the UK, for example press-cuttings, films, oral histories

A further aim was to encourage an awareness of the importance of record-keeping in the AIDS arena, where, for the first time, there was an opportunity to document an epidemic, and the responses to it, as it happened.

A start was made with a checklist of about twenty-five individuals and organisations which previous research for the Programme suggested should be contacted. Further details for most of them were gleaned from the *National AIDS Manual*,[4] an invaluable, and regularly updated, compendium of information on organisations nation-wide concerned in full or in part with AIDS. Further names were added to the original list by recommendation and eventually contact was made with more than forty organisations and individuals in the statutory and voluntary sectors, principally in London and Edinburgh. However, not all of these participated in the survey either because shortage of time prevented it or because they claimed not to keep records. Finally a small sample of existing collections of AIDS-related archive material or information was added to the survey. A full list appears at the end of this article.

Because of the time restriction on the project, the number of contacts was limited to provide a core sample and contact was to be personal, by phone and follow-up visit, rather than by letter or questionnaire. This decision was reinforced by the fact that the people to be contacted would be unfamiliar with the concept of archives. Previous experience had shown that even archivists found difficulty in completing questionnaires about archives and information-gathering was much more likely to be effective through personal interviews. However, a leaflet was written, explaining the aims and objectives of the survey, and copies of this were sent to contacts between phone call and visit to give them some preparation. The utility of the leaflet for its intended purpose proved debatable (often it was not read until the time of my visit), nonetheless, it was something tangible to send to enquirers and saved repetition of the same information.

Details of the initial telephone contacts, reactions and arrangements were kept on conventional index cards. The subsequent visits generated computerised reports of the information gained from the interviews. These reports typically summarised the work/involvement of the organisation/individual, comments or perceptions from the interviewee, details of the documentation produced and conditions for access to it, with my general comments including the long-term prospects for preservation of the material where appropriate.

An interesting and unexpected aspect of the visit was that many of the interviewees, in addition to providing a straightforward account of their work and that of the organisation, took the opportunity of my presence as an objective listener to rehearse the history of their involvement in the AIDS story. These oral histories both informed my subsequent questioning about the archives produced and provided research material from a different perspective for the main Programme.

As anticipated, the interviewees' perceptions of archives could be hazy. In general, the day-to-day work of an archivist is not well known and the archive profession does not have a high profile, so this was not surprising. Archives tend to be thought of in terms of dusty, old parchments and archivists are similarly regarded. It is difficult for people to equate archives with modern papers and much less with letters and documents that they have produced themselves. More authority is given to printed material and on several occasions I was assured that archives were certainly kept only to be shown collections of press-cuttings or leaflets. This is not to denigrate the value of such material as an historical resource but I was interested in the records produced by the organisations themselves, documenting their decisions, plans and activities.

When this has been explained it was usually possible systematically to review the work of the organisation and establish what documentation was produced by its various activities. Often this was done by question and answer based on the information gleaned from the interview, allowing details of the existence, quantity and quality of records to be gathered and noted. Thus there might be committee minutes and supporting papers such as reports; correspondence files; staff records; client files; training programmes and evaluations; annual reports and publications. Obviously the type and quantity of records varied from comprehensive to minimal – one organisation had meticulously documented its activities, keeping a separate bookcase for its archive files, whilst another interviewee when pressed about the records of the outreach sessions he had been describing produced a file containing one sheet of paper with a few scribbled notes. However, in the majority of cases, despite the compelling nature of the work being undertaken, time had been found to maintain records.

Interviewees were then asked to consider the possibility of research use of the material. In general this was welcomed except for confidential files, usually those relating to clients, with the proviso that researchers should be bona fide and/or submit details of their research before access to the documents was agreed. The only exceptions were documents which were covered by legislation, notably records which are designated as public records under the Public Records Acts, 1957 and 1968. These include records of government, for example the Department of Health, and the health service, including the records of the Health Education Authority and its predecessor the Health Education Council. In these cases administrative records are closed for thirty years. This gap in the availability of records central to the study of AIDS in the UK has been compounded by the insistence that all members of government committees are bound by the Official Secrets Act and cannot, therefore, release their personal copies of minutes and papers.

The final consideration was the possibility of long-term preservation of the records which had been surveyed. Public records more than thirty years old, which have been selected for preservation, should be transferred to the Public Record Office, or a place of deposit approved by the Lord Chancellor. Tower Hamlets Health Authority for example, which was included in the survey, has established an Archive Centre which has been so approved and the records of the Authority and its constituent hospitals will be maintained there. The Centre may also take in non-National Health Service health care records from the surrounding area such as those of the Mildmay Mission Hospital, the first AIDS hospice.

In many other cases an existing agency which will assume archival responsibility can be identified. For example the records of the All-Party Parliamentary Group on AIDS might be placed in the House of Lords Record Office, whilst those of the Association of London Authorities, including their HIV Co-ordinator's files, will go to Greater London Record Office. The records of organisations having a purely local remit will usually be of interest to the local authority record office for the area. Examples in the survey are the Aled Richards Trust in Bristol and Druglink in Swindon where the appropriate repositories would be Bristol City Record Office and Wiltshire Record Office respectively. For personal papers also the local record office might be appropriate or there may be a specialist repository such as the Contemporary Medical Archives Centre at the Wellcome Institute in London which would consider taking records relating to the medical aspects of AIDS, either research or treatment.

However, these instances served to confirm an initial feeling that the records most at risk are those of the voluntary sector organisations with a national role, for which there is no existing archival safety net. One of the initial aims of the Programme was to establish an AIDS archive which found general support among the people interviewed. The survey has certainly shown that a repository is needed to safeguard the records of the national voluntary response to AIDS. It has also highlighted the necessity for existing repositories to include AIDS material in their collecting policies. Additionally, there is a perceived need for archival education to prevent the loss of material. Whilst people involved with HIV and AIDS mostly have a realisation of being in the middle of history-in-the-making and welcomed the survey as a first step towards documenting their contribution to the story of HIV and AIDS, they also realise that they need advice and guidance in record-keeping, selection and preservation.

A selection of the survey reports has now been published as *AIDS Archives in the UK* (London, 1990). This also includes an introduction describing the survey methodology and results with an educational section giving guidance on what constitutes an archive and what material should be kept. The survey identified a core sample of AIDS-related archive material with the possibilities for its long-term preservation and demonstrated very positively the archive potential for documenting all aspects of HIV infection and AIDS.

Survey contacts

Statutory sector

Central government
All-Party Parliamentary Group on AIDS

Local government
Association of London Authorities (ALA), HIV Co-ordinator
Local Authority Associations' Officer Working Group on AIDS
Oxford City Council AIDS Liaison Working Party

Health education
Health Education Authority
Lothian Health Board, Take Care Campaign
Scottish Health Education Group

Health service
North West Thames Regional HA, HIV Project
Tower Hamlets HA

Non-statutory sector

Charities
AIDS Policy Unit
AVERT (AIDS Education & Research)
Haemophilia Society
National AIDS Trust

Drug agencies
Druglink, Swindon
Standing Conference on Drug Abuse (SCODA)

Gay organisations
London Lesbian & Gay Switchboard

Health education
Bristol Polytechnic, Faculty of Education
Family Planning Association

Health workers support groups
Forum of HIV Information Workers
Network Association of HIV/AIDS Workers (NOVOAH)

Helplines
National AIDS Helpline
Sussex AIDS Helpline

Hospices
London Lighthouse
Mildmay Mission Hospital

Self-help agencies
Immunity: legal issues and welfare rights
Landmark: drop-in centre
National AIDS Manual
Scottish AIDS Monitor
Terrence Higgins Trust

Business

London International (LRC Products)
Wellcome Foundation

Medical Research

Dr Ray Brettle, Edinburgh City Hospital: HIV/AIDS and pregnancy
Dr Tony Pinching, St Mary's Hospital, London
Dr Roy Robertson, GP Edinburgh: IV Drug Users and HIV/AIDS
Prof. Robin Weiss, Institute of Cancer Research: retrovirologist

Individuals

Ewan Armstrong, Community Health Dept, South Bank Polytechnic
Jonathan Grimshaw, Body Positive and Landmark
Simon Watney, gay historian and activist
Tony Whitehead, Terrence Higgins Trust

Existing collections

British Universities Film & Video Council
London School of Economics Library
Mass-Observation Archive, University of Sussex
National Sound Archive, Hall Carpenter Oral Histories

NOTES

1 J. Foster and J. Sheppard, *British Archives: A Guide to Archive Resources in the United Kingdom* (2nd edn, London, 1989).
2 V. Berridge and P. Strong, 'AIDS policies in the UK: a preliminary analysis', in E. Fee and D. M. Fox (eds.), *AIDS: The Making of a Chronic Disease* (Berkeley, 1992).
3 Royal Commission on Historical Manuscripts, *Surveys of Historical Manuscripts in the United Kingdom: A Select Bibliography* (HMSO, 1989).
4 P. Scott, *National AIDS Manual* (3rd rev. edn, London, 1991).

Index

Numbers in italics refer to Tables and Figures.

Cambridge history of medicine

Health, medicine and morality in the sixteenth century EDITED BY CHARLES WEBSTER

The Renaissance notion of woman: A study in the fortunes of scholasticism and medical science in European intellectual life IAN MACLEAN

Mystical Bedlam: madness, anxiety and healing in sixteenth century England
MICHAEL MACDONALD

From medical chemistry to biochemistry: The making of a biomedical discipline
ROBERT E. KOHLER

Joan Baptista Van Helmont: Reformer of science and medicine WALTER PAGEL

A generous confidence: Thomas Story Kirkbride and the art of asylum-keeping, 1840–1883
NANCY TOMES

The cultural meaning of popular science: Phrenology and the organization of consent in nineteenth-century Britain ROGER COOTER

Madness, morality and medicine: A study of the York Retreat, 1796–1914 ANNE DIGBY

Patients and practitioners: Lay perceptions of medicine in pre-industrial society
EDITED BY ROY PORTER

Hospital life in enlightenment Scotland: Care and teaching at the Royal Infirmary of Edinburgh
GUENTER B. RISSE

Plague and the poor in Renaissance Florence ANNE G. CARMICHAEL

Victorian lunacy: Richard M. Bucke and the practice of late-nineteenth-century psychiatry
S. E. D. SHORTT

Medicine and society in Wakefield and Huddersfield 1780–1870 HILARY MARLAND

Ordered to care: The dilemma of American nursing, 1850–1945 SUSAN M. REVERBY

Morbid appearances: The anatomy of pathology in the early nineteenth century
RUSSELL C. MAULITZ

Professional and popular medicine in France, 1770–1830: The social world of medical practice
MATTHEW RAMSEY

Abortion, doctors and the law: Some aspects of the legal regulation of abortion in England 1803–1982 JOHN KEOWN

Public health in Papua New Guinea: Medical possibility and social constraints, 1884–1984
DONALD DENOON

Health, race and German politics between national unification and Nazism, 1870–1945
PAUL WEINDLING

The physician-legislators of France: Medicine and politics in the early Third Republic, 1870–1914
JACK D. ELLIS

The science of woman: Gynaecology and gender in England, 1800–1929 ORNELLA MOSCUCCI

Science and empire: East Coast fever in Rhodesia and the Transvaal PAUL F. CRANEFIELD

The colonial disease: A social history of sleeping sickness in northern Zaire, 1900–1940
MARYINEZ LYONS

Quality and quantity: The quest for biological regeneration in twentieth-century France
WILLIAM H. SCHNEIDER

Bilharzia: A history of imperial tropical medicine JOHN FARLEY

Preserve your love for science: Life of William A. Hammond, American neurologies
BONNIE E. BLUSTEIN

Patients, power, and the poor in eighteenth-century Bristol MARY E. FISSELL

AIDS and contemporary history EDITED BY VIRGINIA BERRIDGE AND PHILIP STRONG

Mission and method: The early nineteenth-century French public health movement
ANN F. LA BERGE

The meanings of sex difference in the middle ages: Medicine, natural philosophy and culture
JOAN CADDEN