Personal Histories
in
Health Research

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Edited by Adam Oliver

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About the authors

David Blane is Professor of Medical Sociology at Imperial College London. He trained in medicine and sociology, and enjoys teaching medical sociology as an applied subject to large classes of trainee doctors, and as an academic discipline to smaller numbers of interested medical students. For more than twenty years he has researched and published on the topic of social class differences in health, particularly their origin in differential exposure to social disadvantage and, more recently, the way in which social disadvantage accumulates across the life course.

Mike Bury read Sociology at the University of Sussex. He worked at Bristol and Manchester, before taking up a lectureship at Bedford College (later, Royal Holloway) in the University of London to work with Margot Jefferys in 1980. In 1991 Mike Bury was appointed to a personal chair in Sociology in the University of London. Throughout his time at Royal Holloway, he was closely associated with the MSc in Medical Sociology. His main research interests have been in chronic illness, disability and ageing, and on wider aspects of culture and medicine, and he has conducted both qualitative and quantitative studies in these areas. He was co-editor of the journal Sociology of Health and Illness between 1995–2001, and in 2001 completed a four year term on two boards of the Medical Research Council. He is also a Fellow of the Royal Society of Arts.

Anna Coote is a senior executive at the Healthcare Commission, which she joined in 2005 to head its work on patient and public involvement. She was formerly Director of Health Policy at the King's Fund, Deputy Director of the Institute for Public Policy Research, adviser to the Minister for Women, a Senior Lecturer in Media and Communications at Goldsmiths College, London University, a producer and editor of current affairs and documentaries for Channel Four TV, Deputy Editor of the New Statesman, and a journalist and broadcaster. She is a member of the UK Sustainable Development Commission.

Sir John Grimley Evans is Professor Emeritus of Clinical Geratology at the University of Oxford and recently retired from the post of Consultant Physician in Geriatric and General (Internal) Medicine to the Oxford Hospitals which he had held since 1985. Prior to that he had been Professor of Medicine (Geriatrics) at the University of Newcastle-upon-Tyne, following a period as Lecturer in Epidemiology at the London School of Hygiene and Tropical Medicine. Educated at the Universities of Cambridge and Oxford he pursued postgraduate training in clinical medicine and epidemiology in Oxford and at the University of Michigan USA. Experience as member of a New Zealand team studying the

effects of migration on the health of Polynesian populations in the South West Pacific led to research interests in epidemiological approaches to the prevention and management of disability in later life. Recent work has focused on dementia. A Vice-president of the Royal College of Physicians 1993–95, he was also a member of the Medical Research Council and Chairman of its Health Services and Public Health Research Board 1989–94. He served as Editor of Age and Ageing 1988–95, and Senior Editor of the Oxford Textbook of Geriatric Medicine.

Professor Raanan Gillon is a hybrid GP and philosopher and Emeritus Professor of Medical Ethics at Imperial College London, where he still does some teaching, especially on its MSc in Medical Ethics, and on its one week intensive course in Medical Ethics which he started in 1983. He is Chairman of the Institute of Medical Ethics and Deputy Chairman of the British Medical Association's Medical Ethics Committee. He was editor of the Journal of Medical Ethics for twenty years until 2001, and retired from part-time NHS general practice at the end of 2002.

Professor Walter Holland qualified from St. Thomas' Hospital Medical School in 1954. His interests in epidemiology were aroused by his involvement in investigations of the 1957 influenza pandemic while doing his national service in the RAF. After gaining further experience in epidemiology at the London School of Hygiene and at Johns Hopkins University School of Hygiene, he returned to St. Thomas' in 1962, where he founded the Department of Public Health Medicine and directed the Social Medicine and Health Services Research Unit. Since retirement in 1994, he has been Visiting Professor at the London School of Economics. His major research interests have been in the epidemiology of chronic respiratory disease and the application of epidemiological principles to health services research. He was President of the International Epidemiological Association and of the Faculty of Public Health Medicine.

Professor Alison Kitson is Executive Director of Nursing at the Royal College of Nursing (RCN). As part of the RCN's top team she is responsible for leading on the organisation's professional nursing agenda and to help it deliver its mission to represent nurses and nursing, promoting excellence in practice and shaping health policies. Previous to this post she was Director of the RCN Institute, responsible for the delivery of professional development, lifelong learning, research and clinical practice support services to members. As Director

she instigated and has supported the development of a number of innovative projects including the RCN's work on Knowledge Utilisation and Transfer and an extensive set of practice-based research programmes. She has a distinguished academic and professional career and has published over 100 academic and professional articles, representing nursing on many local, national and international stages. In 1991 she was awarded a Fellowship of the Royal College of Nursing for her work on Standards of Care. She is a supernumerary Fellow of Green College Oxford, holds a number of Visiting and Honorary Chairs, and in 2001 was awarded Distinguished Graduate of the Year from her old university, University of Ulster.

Professor Rudolf Klein was born 1930 in Prague. Educated in the UK (MA in History at Oxford), he spent the first half of his career as a journalist with the London Evening Standard and The Observer. The second half has been spent as an academic. He was Professor of Social Policy at the University of Bath (1978–1998), and is now Emeritus Professor there. Currently, he is Visiting Professor at the London School of Economics and at the London School of Hygiene. He was awarded the CBE in 2001, and in 2002 was elected to the US Institute of Medicine. At present, he is researching the latest wave of institutional innovation in Britain's NHS Foundation Trusts.

Robert Maxwell's background is in general management, with an emphasis on policy and finance. He worked first in an international mining group, and then in McKinsey and Company, where he became intensely interested in the health services field. During his time at McKinsey's, he advised on health issues in the UK, the US, the Republic of Ireland, the Netherlands and elsewhere. He drew on this experience in a study (published in 1974) on these issues in some 20 developed countries, and later took a related PhD at the London School of Economics. From 1980 to 1997 he was Chief Executive of the King's Fund, the London-based independent organisation concerned with health policy, management and practice. He lives in Gloucestershire where, since 2002, he has chaired the Gloucestershire Partnership NHS Trust, which provides mental health and learning disability services in the county. He is also a Trustee of the Joseph Rowntree Foundation, the country's leading independent sponsor of social policy research.

Adam Oliver is Senior Research Fellow and Deputy Director of LSE Health and Social Care, one of the largest research institutes in the health-related social

sciences in Europe. He is Founding Chair of the Health Equity Network, Founding Coordinator of the Preference Elicitation Group, and a former Coordinator of the European Health Policy Group. He is also Founding Co-Editor of the journal, Health Economics, Policy and Law. He has published quite widely in the areas of health equity, economic evaluation, risk and uncertainty, and the economics and policy of European health care reform.

Jennie Popay is Professor of Sociology and Public Health at the University of Lancaster, and Director of the newly established Collaborating Centre for Community Engagement in England. She spent five years teaching in East Africa and then studied in New Zealand before beginning her research career at the Unit for the Study of Health Policy at Guy's Hospital in London at the end of the 1970s. Since then she has worked as a sociologist in social policy and public health in academia, the voluntary sector and the NHS. Her research interests include social and gender inequalities in health, the sociology of knowledge, the evaluation of complex social interventions and evidence synthesis. She has published widely on these subjects in academic, policy and popular media. She has a particular interest in developing the role of qualitative research in public health, and was a founding convenor of the Qualitative Research Methods Group within the Cochrane Collaboration and the Implementation Process Methods Group in the Campbell Collaboration. She has held public appointments as a non-executive director of a community healthcare trust, chair of a local Child Development and Early Years Partnership Board, and was a commissioner with the Commission for Health Improvement. She is currently a commissioner and vice chair of Commission for Patient and Public Involvement in Health.

Albert Weale has been Professor of Government and co-editor of the British Journal of Political Science at the University of Essex since 1992. Before his appointment at Essex, he was Professor of Politics at the University of East Anglia (1985–92), and before that Lecturer in Politics (1976–85) and Assistant Director of the Institute for Research in the Social Sciences (1982–85) at the University of York. His principal publications include Equality and Social Policy (Routledge and Kegan Paul, 1978); Political Theory and Social Policy (Macmillan, 1983); The New Politics of Pollution (Manchester University Press, 1992); with others, The Theory of Choice (Blackwell, 1992); Democracy (Macmillan, 1999); and, with others, Environmental Governance in Europe (Oxford University Press, 2000). He has also been active in various public and charitable bodies. Between 1986 and 1990 he was a member of the Advisory

Board of the King's Fund Health Policy Institute and between 1996 and 2001 he chaired the Fund's Grants Committee. He also chaired the Working Party on The Ethics of Xenotransplantation, established by the Nuffield Council on Bioethics, which reported in 1996. He was a member of the Nuffield Council on Bioethics between 1998–2004.

Professor Alan Williams was one of the UK's leading health economists, and a founding father of the discipline. Over recent decades, his main interest was in the area of explicit priority-setting based on the cost-effectiveness approach, applied both to health maximisation and to the reduction of inequalities in people's lifetime experience of health. He was anxious to clarify the ethical issues involved in such a process. He spent most of his career at the University of York, and in July 2002 was elected a Senior Fellow of the British Academy, the first health economist to receive that honour. He died in June 2005.

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Healthy lives: reflecting on the reflections

Adam Oliver

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No man's knowledge here can go beyond his experience

John Locke – Essay concerning human understanding II

Introduction

A conversation with Rudolf Klein on a flight between Vienna and London in the Autumn of 2003 sparked the idea for this book. It struck me that Rudolf, when reflecting on his plans to retire entirely from academic pursuits come his seventy-fifth birthday, ought to attempt to produce a short autobiography before hanging up his pen. Rudolf has been, to my mind, one of the most important UK health policy scholars of the last thirty years, and I felt it would be a shame if he left the field without producing an account of his time on it.

During our conversation, Rudolf, whilst being too modest to state explicitly that his experiences would be of much interest, generally concurred with the above point of view. He did explicitly state, however, that others who have been working in the field of health-related research over the past several decades might have interesting stories to tell. Moreover, we both felt that such stories had the potential to be more than merely sentimental journeys. Rather, that they could be genuinely informative, by offering current and future generations of scholars lessons on at least some matters that they can reasonably expect to experience during their own careers, and ideas for how they might choose to react to these experiences. Of course, one could argue that the fruition or 'product' of an idea has its time and place (a point to which I will later return), with modern path dependency theorists arguing that what has or has not worked in the past is not necessarily a good predictor of whether it will work now or in the future (Hacker 2002). But it must surely be the case that the experiences and knowledge[1] of those who have gone before can in many instances serve as a rich and valuable resource, and can often help to avoid the reinventing of the wheel and the repeating of past mistakes.[2]

Rudolf was probably quite relieved to leave me at Gatwick, possibly expecting that he would not hear much from me regarding our 'project'. But I went home and started thinking about whom we might invite to contribute. The focus was intended to be the UK, so clearly I focussed my thoughts on those who have devoted a good deal of their careers to UK health-related issues. I considered only those who I felt were quite eminent in their own particular area of expertise, and also gave some thought to attaining a gender and disciplinary mix. For various reasons, some people declined to contribute. Had they accepted, perhaps the insights offered by this collection would look very different, possibly highlighting why knowledge may often be the consequence of selection.

Although, in some cases, I had been familiar with their work before, I originally met a number of the contributors through their involvement at one time or another with the Health Equity Network[3], namely Rudolf, David Blane, Anna Coote, Sir John Grimley Evans, Raanan Gillon, Walter Holland and Albert Weale. I was acquainted with the late Alan Williams a few years prior to

the others when I was a postgraduate student at the University of York, and Mike Bury and Jennie Popay were suggested to me as people to have on board to present additional sociology and public health perspectives. At the beginning of 2004, all of the above were invited to contribute, and first drafts were presented at a meeting held at the Nuffield Trust in September of that year. During the meeting, it was decided that it would also be potentially beneficial if we solicited contributions from Alison Kitson, to offer a nursing perspective, and Robert Maxwell, to offer a perspective from a funder of research in the hope that we may learn, in the words of Albert Weale, what the puppeteer makes of the dances of his puppets. Thankfully, both willingly accepted the invitation, swayed perhaps by knowing who the other contributors would be at the time of receiving their invitations.

The contributors were not given detailed terms of reference for their chapters. They were simply asked to relate how they became involved in their vocation, how they saw the development of their own career and that of their area of research, the lessons they have learned, and their perspectives on how research should develop in the future. Moreover, the contributors were asked to offer their own personal 'stories', not fully referenced 'academic' pieces. I felt that to have given them more detailed requirements than these would have curbed their enthusiasm for the project, and would have run the risk of having them write not their own stories, but my perception of what their stories ought to be. The main purpose of this introductory chapter is to offer a few thoughts on some of the issues that strike me as important in the creation and dissemination of knowledge from my reading of the 'life stories' presented in this collection.

The role of chance

The stories given in this book indicate that many people in health-related research and policy enter the area by accident and/or have careers at least partly guided by chance. For example, Rudolf Klein entered research as he had to abandon journalism (specialist topics: opera and football); Walter Holland, partly because he owned a car. Anna Coote's career has followed a particularly serendipitous route across media, think tanks, academia and government, although unlike most of the other contributors, it seems that it has never been Anna's intention to be a career academic and that she has, on the whole, pursued her interests. Other careers have been much more 'static', most notably David Blane's, who has been working on a particular set of issues in the same office in London for the past thirty years. By and large, however, much of the knowledge that the contributors have produced over the last several decades has been dependent upon chance events.

An influential type of chance event that many of the contributors have in

common concerns the importance of meeting early supporters and/or mentors. As Jennie Popay notes, luck and the good graces of others is at least as important as deliberative action to the development of a career, and Sir John Grimley Evans points out that fate plays an important part in one's career, as meeting different people at different times can drive one's research and the type of research that one is involved in. Names of mentors that run through the chapters include Jerry Morris, Margot Jefferys, George Brown, Robert Maxwell, Gordon McLachlan and John Wyn Owen. It seems that influential individuals can in part determine the knowledge that is produced by those that follow them. They therefore carry a heavy responsibility, and it is important that academics do not encourage their students and younger colleagues to follow them uncritically, but to encourage the critical appraisal of information and argument.

A similar line can be taken with respect to the funders of research. Although knowledge is to a significant extent constructed by the interests and perspectives of intellectuals, funders play a large part in determining what knowledge is actually produced. This is potentially problematic. For example, government departments may often frame the projects that they fund strictly in line with current, already-decided-upon, policy. Moreover, Walter Holland states that officials are likely to ignore or even suppress information that they do not agree with, and that their occasional refusal to accept that some issues of policy relevance even exist can hinder research. Similarly, Grimley expresses the difficulties of dealing with politically motivated attempts by government to suppress health services research when they do not want its results to be known. In this regard Rudolf points out that the Foundations, such as the Nuffield Trust, the King's Fund and the Milbank Memorial Fund, have offered an important service, by giving greater room for free thought and by identifying new themes, challenges and talent.

Inspirational and/or supportive mentors/funders can thus be a good or a bad thing for knowledge creation, but seem to be crucial if one is to have a successful career as a researcher (or indeed anything else). The presence or absence of a supportive mentor may be an important determining factor in whether people pursue or abandon research careers, or in the direction that their research takes. Political beliefs are also heavily determined by chance, in their being influenced by our parents, schooling and other factors related to our backgrounds over which we do not have much choice. But whereas the chance event of meeting an inspirational mentor may lead people in directions that they may not have otherwise taken, their pre-existing political beliefs are likely to somewhat 'fix' the underlying areas of research that they engage themselves with. In short, inspirational contacts are serendipitous and may broaden our 'secondary' options; underlying political beliefs or 'values' may intrinsically restrict our 'primary' options.

David Blane, Jennie Popay and Albert Weale all cite early political influences as a causal factor for their involvement in health-related research, and I suspect that a left of centre leaning led many of the contributors towards their involvement in this area. The topic of health inequalities, in particular, attracts those with strong political beliefs. Unfortunately, over-politicising academic research is inevitably divisive, and runs the risk of undermining interdisciplinary debate, an important problem if one takes the view expressed by Albert that the best way to create 'knowledge' is by gathering people from a range of disciplines to ponder and deliberate complex policy-related problems.

In the next two sections I consider in turn two issues, touched upon above, that almost seem like a paradox. Namely that intellectuals should not be complacent in losing sight of their self-critical stance, and yet, equally, they should not lose sight of what matters to them.[4]

The importance of self-criticism

In their (in my view) fascinating published dialogues, Daniel Barenboim and Edward Said discuss the contrasting roles of the politician and the intellectual or artist (Guzelimian, 2004). They state that politicians, with the exception of rare visionaries such as Ghandi and Mandela, necessarily adopt a position of compromise, but that the 'true' intellectual/artist, on the other hand, ought never compromise his or her views. This does not imply that the intellectual/artist ought not be self-critical. On the contrary, in good critical rationalist tradition (Popper 1963), the intellectual/artist ought to be the sternest critic of his or her own views and ideas. But it does imply that one ought not compromise one's views *merely* to please, for example, a funder, journal referee or co-author, because such compromises equate to intellectual timidity.

These views are relevant to the contributions in this book. For example, in his chapter Alan Williams expresses the spirit of non-compromise quite fiercely, in his utter conviction in the merits of quality-adjusted life years (QALYs). I believe that Alan's conviction was sincere, and if one accepts the Barenboim/Said reasoning, his unwillingness to compromise his beliefs implies that he had at least some of the attributes required of a fine intellectual. It may also be the case that Alan, over a protracted period of time, had considered carefully all of the arguments against QALYs and had concluded that their limitations are an insufficient excuse to refrain from championing their potential benefits. Of course, it is possible that he was right, and his views are implicitly supported by Mike Bury who points out that a focus upon improving quality of life rather than reducing mortality is of increasing relevance in countries – like the UK – with ageing populations, which offers a sense of practical 'urgency' to many of those who occupy themselves with the QALY debate. A consideration of health

outcomes, and more specifically quality-adjusted health outcomes, is therefore appropriate. But given the many forceful arguments that can be waged against QALYs, that range from the technical, to the ethical, political and institutional, it is tempting to conclude that their supporters could usefully undertake more critical reflection on the technical and practical limitations and ethical implications of this particular measure of health outcome.

Insufficient self-critical reflection is not specific to the advocates of QALYs. Many intellectuals perhaps spend too much time defending both their own work/ideas, and implicitly the conceptual basis of their particular disciplinary perspective. Ideally, for the better advancement of knowledge, they ought to devote as much critical attention to their own views as they do to the views of others. A failure in this respect probably in part reflects a general reluctance to question the product of many years of investment, and as such is perhaps intrinsic to human nature.

A lack of self-critical reflection by some academics may also, in part, be the product of an excessive desire to influence, when they should be aiming merely to be heard.[5] Academics, particularly in an arena as 'practical' as health-related studies, should of course endeavour to inform policy as a *means* to improve social welfare; but influencing policy ought not be the *end* in itself. There is a fine line between the dissemination of one's own work and advocacy. One could define dissemination as the active diffusion of one's work in a 'balanced' manner, in full recognition of any limitations and counter-arguments, and advocacy as the active, often aggressive, diffusion of one's work without an adequate explication of the limitations and counter-arguments, which may arise when the will to influence supplants the responsibility to inform. An impatience caused by the desire to have a policy impact may cause many academics to cross the dissemination/advocacy line. It is therefore important for us to attempt to guard against advocacy in academia, as it can lead to intellectual entrenchment, the perpetuation of intolerance to new ideas, and sub-optimal scientific development.

The importance of underlying values

When I refer to an underlying 'value' I mean something that is more 'fundamental' than, say, Alan's belief in the merits of QALYs or David Blane's concern with inequalities in health outcomes. Alan cared and David cares deeply about social justice, but yet so do many people who believe in neither QALYs nor a focus upon health outcomes inequalities. It is their belief in improving social justice that is fundamental, and it this value judgment that may cause many intellectuals to choose health and/or health care as their domain of interest.

Given the above stated concerns about the lack of self-critical reflection

among those who produce knowledge, ought there be a place for underlying values, or 'ideology', or, in Rudolf's terms, theology, in science? It is difficult to see how there cannot be a place. We are all influenced, to a greater or lesser degree, by our own personal views about what is best for the world. But people sometimes seem to confuse their 'second order' beliefs (e.g. QALYs, health inequalities[6]) with their fundamental values, which can lead to intellectual rigidity. This is problematic, as a willingness to listen carefully to the views of others, and potentially to revise our views, is beneficial to the development of knowledge. Of course, if intellectuals were to change their opinions too frequently, they could be charged with being corruptible. The marriage of intellectual flexibility and non-compromise over what really matters to us is difficult to achieve. Nonetheless, ideology, although it does and should matter in shaping one's fundamental convictions, should not be an excuse for a lack of self-critical reflection.

I earlier argued that academics should seek to disseminate rather than advocate, but that encouraging people to take note of one's work is a difficult task, and those who pursue dissemination with any serious intent may inevitably find themselves slipping into advocacy. In the next section I consider some issues with respect to informing the policy debate.

Getting the message across

In the absence of an audience, most areas of intellectual endeavour are pretty pointless. Academics should therefore seek to disseminate their work, in a balanced manner, to those whom they wish to inform. It is sometimes said that many academics are not particularly good at disseminating their work to policy makers, possibly because the academic career structure rewards publication in specialist journals rather than efforts to make arguments and findings comprehensible to non-specialists. Therefore, dissemination to fellow specialists may be more complete than dissemination to those more directly engaged with policy.

For this reason, some argue strongly for making the policy-relevant academic literature more accessible (Lomas, 1997), and it has been suggested that some people be employed as full time professional 'knowledge brokers'. I recognise the potential benefits of knowledge brokers, particularly if they are able to distil 'specialist' knowledge that academics (or others) either fail to disseminate or disseminate without sufficient critical reflection. However, I would personally urge a degree of caution with respect to the idea of creating a profession of knowledge brokers, because it may often be the case that those without intimate knowledge of the context, methods and/or data of a study will misinterpret the relevance of the study's findings. Moreover, given that arguments are often complex and nuanced, recruiting middle men to broker knowledge between the

intellectual and the policy maker runs the risk of formalising a system of Chinese whispers.

In order to reduce the risk of misinterpretation, it might be better to provide incentives for those who produce research to write accessible summaries of their own work, although the danger remains of losing the nuance that is so often critical in offering a balanced argument. In some contexts it might even be beneficial to involve the policy maker or practitioner in the process of producing research. Alison Kitson relates her observations of resistance to innovation in maternity care by those who felt threatened by new methods, and it is possible that this resistance may have been less pronounced had there been greater collaboration at an early stage of the research.

However, to reiterate, it is important that dissemination by the intellectuals themselves does not descend into advocacy. Given that some academics tend to step over the advocacy line, the policy maker, by making as much effort as possible to understand an argument or piece of evidence, shares some of the responsibility in guarding against this. The public financing of full time knowledge brokers to work closely with academics might offer a *partial* solution. But in order to avoid the problem of Chinese whispers, the knowledge brokers would need to be as analytically capable as the academics, and would need to make great efforts to understand the full context, and limitations, of the academics' work. Moreover, it is important to guard against the possibility that the knowledge brokers might be 'captured' by various interest groups and thus become advocates themselves.

The media may also be used to disseminate knowledge, and, indeed, Mike Bury makes the point that media coverage probably has more effect than academic debate on social and/or policy change. In some contexts, for example in its coverage of global catastrophes, the media can serve the social good. But despite the apparent tendency for academics, largely for reasons of self-aggrandisement, to increasingly court the media, newspapers and television generally provide a poor picture of academic argument and evidence, not least because journalists have their own career imperatives that may centre around readership and viewing figures. As Anna Coote, herself a former newspaper and television journalist, writes, it is very difficult to strike a balance between forensic precision and easy reading,[7] and television production values abhor complexity, nuance and anything that takes too long to explain.

Notwithstanding the imperative to present ideas and evidence in a balanced manner, there are of course situations where existing practices are retained when they are quite clearly suboptimal, which frustrates academics who disseminate evidence of better practice. Walter Holland, for instance, feels that in his fifty plus year career, his research has only rarely had a major impact at the practice level. As both Rudolf and Alison note, the timing of research is as important as

its quality in determining whether it will have an influence,[8] for which there are several possible reasons.

For example, Albert Weale intimates that the culture of some institutions may simply be resistant to change. Alternatively, it might be the case that those involved in existing practices do not address those practices critically enough. Mike Bury, for instance, argues that criticism can be irritating to many if it does not conform to the dominant assumptions, or if the criticism is arrogant or disrespectful. Also, existing practices and policies may suit the prevailing balance of interests, an argument that is central to historical institutional theorists in their explanation for why policies tend to be path dependent (Hall and Taylor, 1996), or they may, as Rudolf suggests vis-à-vis consumerism in health care, fit the prevailing societal 'mood', against which even Prime Ministers might find themselves powerless. In areas over which governments can exercise power, policies and practices may not stand much chance of being accepted unless they conform to the overall political 'vision' (Nutbeam, 2001), with a radical change in political vision being one possible conjunctural force that could possibly lead to departures from the policy/practice path. This latter explanation is the main reason why many health inequalities specialists, such as David Blane, suddenly found themselves at the centre of the health policy agenda following the Labour Party's election to government in 1997.

If academics think that they are being ignored, they should not become too disheartened. Political factors largely determine whether knowledge is used or ignored, and the actual practice of politics (as opposed to the analysis of the practice of politics) ought not be the academic's domain. Ignored or not, academics should continue disseminating their views and evidence in as balanced a light as possible, without using 'spin' to convince people that they are right in any objective sense.

Conclusion

I have presented some fairly random thoughts on the creation and dissemination of knowledge. My highest hope for these is that they might stimulate further thought and debate. From the fascinating personal histories presented in this collection I of course could have raised many other issues, but I will leave all else for another place. For now, I will endeavour to practice what I preach and continue to critically reflect upon the views that I have expressed in this chapter. Most people might well disagree with everything I have written, and I am perfectly willing to accept that I may be wrong. Perhaps in time I too will come to disagree with everything I have written here; Bertrand Russell defended himself against those who found inconsistencies in his writings by noting that it is foolish to rigidly refuse to change one's views over time. But, at this moment in time,

I, on balance, agree with what I have written. I seek to learn, criticise, construct and disseminate, and I have certainly learned from the contributors to this book. And whilst I recognise that we all have some fundamental values over which we are not willing to compromise, I hope that those who read this book read it critically, so that I might learn some more.

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Notes

1 The Oxford English Dictionary's various definitions of knowledge include: awareness or familiarity gained by experience; a person's range of information; a theoretical or practical understanding of a subject; the sum of what is known; true, justified belief.

2 As is detailed in their chapters, at least three of the contributors (David Blane, Mike Bury and Jennie Popay) have used personal biography as a research method in attempting to better understand the factors that influence people's health.

3 www.ukhen.org

4 Throughout this chapter I use the terms 'intellectual' and 'academic' interchangeably. There are some who may question the wisdom of this assumption.

5 This point is complicated to some extent vis-à-vis the contributors to this book because some of them have/have had jobs that directly involve influencing and/or making policy. Therefore, it is probably slightly more difficult for people with these experiences to refrain from enthusiastically advocating what *they* see as best practice.

6 In his chapter, Raanan Gillon refers to the basic tension between the different domains of equity as the conflict between 'outcomes justice' and 'autonomy justice'; i.e. that a concern for greater equality in outcomes may

necessitate unequal freedoms and vice-versa. Therefore, people who share a concern with improving social justice may have diametrically opposing views on how justice is best served.

7 cf. knowledge brokers.

8 For an interesting read on how the timing of events influenced the success or otherwise of health care reform initiatives in the UK, the US and Canada, see Hacker (1998).

2

Health inequalities: from science to policy

David Blane

A pathology textbook (Thomson and Cotton, 1962) introduced me to health inequalities. Each of the major diseases was described under a series of standard sub-headings – aetiology, natural history, cellular pathology and so forth. Under the aetiology sub-heading of nearly every disease, the textbook reported: *...more common in social class V than in social class I* (ischaemic heart disease, at that time, was a notable exception). I was struck by the embarrassed disdain with which my pathology lecturer dodged a question about the meaning of this recurring phrase. The embarrassment, I believe now, was caused by the fact that he did not know the answer, and quite possibly had never thought about the topic nor previously been questioned about it. His disdain implied that, at a respectable medical school, one preferred to ignore such matters. Interestingly, the only clinician who mentioned class was Phillip Rhodes who, as well as being Dean, was Professor of Obstetrics and Gynaecology, where social class differences in infant and maternal mortality had long been an issue of concern.

I studied pathology in 1967, reading a second-hand textbook. The 1961 Decennial Supplement on Occupational Mortality (Registrar General, 1971), which would have provided the then most up-to-date information about social class differences in disease-specific mortality, was not published until 1971, so the information in my pathology textbook must have come from the 1951 Decennial Supplement, when class differences in mortality were reportedly small in comparison with their later widening; a later widening which forced even the most respectable of medical schools to recognise their existence.

I came across health inequalities next in the film *Praise Marx and Pass the Ammunition*, where class-specific standardised mortality ratios were deployed as weapons in the class struggle. These data would have come from the 1961 Decennial Supplement, about which, in his introduction, the then-Registrar General, Michael Reed, said: *...the groups of men who were classified* (social class) *V in 1949–53 did not benefit from the considerable benefits of the decade as did the majority of their compatriots.* The 1961 Decennial Supplement also reported a pilot study comparing social class at death registration with social class at census, the results of which were sufficiently worrying[1] to justify expenditure on what became the OPCS (later ONS) Longitudinal Study.

In 1970 I completed my pre-registration year as a house surgeon and house physician, and gained by so doing the security of registered medical practitioner status – a security that I used to pursue an interest in social class differences in health and, more generally, public health (my six months as a house physician had convinced me that prevention is better than cure; not least because the latter mostly is a misnomer for *remission*, upon which patients are returned to the living and working conditions that caused their ill-health in the first place). My earnest inquiries about a career in public health were rebuffed by the then-standard advice: *go away, and don't come back until you've got 10 years clinical practise*

under your belt. Undeterred, I used my initiative, and asked myself where else could I learn about social class differences in health. Ah, I thought ... social science.

In London at the time there were two possibilities: Professor Jerry Morris' MSc in Social Medicine at the London School of Hygiene and Tropical Medicine; and Margot Jefferys and George Brown's MSc in Medical Sociology at the Bedford College (the latter having been started to, among other things, supply the lecturers in medical sociology that the London medical schools would require as part of their implementation of *The Todd Report* on modernising medical education). By chance, I talked first with Margot Jefferys, who persuaded me to sign up to her course. After a one year catch-up course in general sociology, I started my postgraduate studies in medical sociology where, much to my surprise, there was almost no mention of social class differences in health (and the only copy of the 1961 Decennial Supplement was the personal property of one of the research workers, a political refugee from the Greek colonels' recent *coup d'etat*). So, a year later I found myself little wiser about social class differences in health, but qualified to teach medical sociology to medical students.

I taught medical sociology at Charing Cross Hospital Medical School, Westminster Hospital Medical School, St Mary's Hospital Medical School and King's College School of Medicine; and in all of them the lecture on social class caused a riot, sometimes literally. At one medical school, I was hauled before the Dean, where the President of the Students' Union reasoned: *We don't need to learn about social class, because, for example, I can see the working class from my train window when I go through south London*; to which the Dean replied: *A fair point, don't you think, Dr Blane?* Through all of this, Margot Jefferys was my bedrock support, both privately and in public. Looking back, I am uncertain why Margot went to such lengths to protect me, unless perhaps she recognised someone who was equally serious about her discipline. After one examiners' meeting, though, at which she had defended eloquently my teaching of social influences on health, she said to me privately: *Really it's all due to selection, you know – you should read Raymond's* (Professor Illsley) *1955 paper* (Illsley, 1955).

Raymond Illsley's work was given similar prominence by Sir John Brotherstone in his 1975 Galton Lecture, *Inequality: Is It Inevitable?* (Brotherstone, 1976). Brotherstone listed five types of possible cause of social class differences in health, and reviewed the evidence for each of them. The *influence of intelligence and education* and *behaviour and value systems* were given some attention, as were *health service deployments*. The *biological effects of deprivation* were mentioned, primarily in relation to the *'environmental' component of reproductive efficiency*. Pride of place was given to *definitions of social class* which to Brotherstone meant selection – the upward mobility of the physically and mentally well endowed, and the downward mobility of the less blessed.[2]

Around the same time *New Society* published Richard Wilkinson's open letter (Wilkinson, 1976) to David Ennals, the then-Minister of Health and Social Security, inviting him to think about health inequalities and the social determinants of health. This challenge coincided with the introduction of the Resource Allocation Working Party, which channelled money away from the London teaching hospitals (and their influential consultants). Some insiders speculate that consultant discontent created a problem for Ennals to which Wilkinson's letter provided the germ of a solution – the possibility, for example, that health inequalities could be tackled by channelling funds to deprived inner city areas where, coincidentally, most teaching hospitals were located. Whether or not this speculation is correct, David Ennals established a research working party on social inequalities in health, chaired by Sir Douglas Black, the then President of the Royal College of Physicians.

In retrospect the *Black Report* (Black *et al.*, 1980) seems a solid, consensual document, with which only Castlereagh conservatives could disagree. I learned later that this was not how it appeared to those involved. A rather anodyne draft was given clarity and direction as a result of prolonged debate and re-drafting by Jerry Morris and Peter Townsend, the working party's experts in social medicine. Their achievements become obvious when their conclusions are compared with those of Sir John Brotherstone five years earlier. Gone are Brotherstone's concern with intelligence and health service deployments; selection lost its prominence; and prime place was given to a far less restricted version of what Brotherstone had called the biological effects of deprivation. Generally, Brotherstone and Black appear to belong to different eras. The *Report*'s recommendations were costed at a level which the new Conservative Government regarded as unrealistic, and, in truth, probably would have similarly terrified a Labour Government had it been re-elected.

Somewhat strangely, I remember at the time being distinctly unimpressed by the *Black Report*. I had been lecturing on social class differences in health for nearly ten years, and felt that the *Report* added little to what I had been teaching my students. Also, I disagreed with the emphasis on childhood in the *Report*'s recommendations, and was critical of its neglect of the workplace as a source of inequalities in health. I was much more impressed by the 1971 Decennial Supplement (Office for Population Censuses and Surveys, 1978), which had been published two years earlier, and which I regard still as exemplary.[3] Nevertheless I learned quickly that the *Black Report* had started a public debate about health inequalities, and had shifted the emphasis of the academic debate from selection to causation. At a personal level, I started to structure my writing and lectures around its explanatory framework – such is the difference in intellectual influence between a junior lecturer and a government working party, even one which a later government tries to suppress.

The next decade was crucial for health inequality research. One after another the theories which attempted to explain away the phenomenon of social class differences in health were tested and found wanting. John Fox and Peter Goldblatt (1982) used the OPCS Longitudinal Study to show that health inequalities were not an artefact of the previously mentioned mismatch between social class as recorded at death and at census, and they were joined by David Jones (Fox *et al.*, 1985) to show that the mortality gradient could not plausibly be created by health selection. Elsie Pamuk (1985) painstakingly re-classified successive decennial supplement data to a single version of the Registrar General's classification, and by so doing was able to demonstrate that widening inequalities were not an artefact of changes to the Registrar General's classification. Michael Marmot, Martin Shipley and Geoffrey Rose (1984) used Whitehall Study data to show that the mortality gradient survived statistical control for behavioural risk factors, and that socio-economic differences in mortality risk could be explained only in part by social differences in health behaviour. A series of intervention studies, based on the behavioural approach, failed to produce the predicted improvements in mortality (MRFIT, 1982; Rose *et al.*, 1982; Rose *et al.*, 1983). Michael Wadsworth (1986), on the retirement of James Douglas, took over the National Survey of Health and Development; and was able to show that childhood illness, in this 1946 birth cohort, was too rare for any health selection to make a significant contribution to the social gradient in health. Richard Wilkinson (1986) pulled together this body of work, in the form of an edited volume, which remains an important stepping-stone in the history of health inequality research.

I was aware of this work from a distance. My priority at the time was learning to teach medical sociology as a clinically relevant subject, to which end I spent one day each week in general practice at the Forest Road Health Centre in North London, where under the supervision of Dr Ron Singer I was able to identify the areas of overlap between the academic discipline of medical sociology and the clinical problems brought to the surgery by our patients. At the same time I was becoming convinced of the need to study health inequalities in terms of the way exposure to aetiological factors tend to cluster during any one phase of life and the tendency for these exposures to accumulate across the different phases of life (Blane, 1985). I used my afternoons at Forest Road to explore this idea through open-ended interviews with some of the practice's older patients. Also, around the same time, I attended the British Sociological Association's annual conference on *History and Sociology* where I learned about calendar studies; in particular, the work history calendars used by Duncan Gallie and Frank Beckhoffer in their *Social Change and Economic Life Initiative* (Gallie, 1988). From these sources, I developed the idea that a lifegrid could be used to collect retrospective data about accumulated exposure to health hazards across the life course.

Once I had developed the lifegrid (Blane 1996), I started to use my afternoons at Forest Road to conduct lifegrid interviews with patients suffering from respiratory disease. Later, in 1987, I wrote up one such interview (Blane, 1987):

"Mrs E is 57 years old. She suffers from shortness of breath, which for periods occurs even at rest, coughing copious volumes of sputum for months on end during the winter and frequent infections in her lungs. Her general practitioner notes, with their accompanying out-patient reports and in-patient discharge summaries, record a diagnosis (chronic obstructive airway disease) and much serious and sympathetic consideration of her treatment regime, which involved treating the chest infections, reducing the airway obstruction with bronchodilators and inhaled steroids and persuading her to stop smoking. Little attention was given to the cause of her chest pathology and, to the extent that this question was considered, it was assumed to be due to smoking. Mrs E's (lifegid) interview, however, uncovered the following.

Mrs E has lived her whole life in the same area, apart from three years during the Blitz, when she was evacuated to Surrey. She remembers yellow-black smogs from her childhood to the early 1950s (there were four gas works in the area), and since then the High Street has become a heavily used, and heavily polluted, main road. Mrs E and both her siblings had 'bad chests' when young. Their father was a compositor in the printing trade, and 'in and out of work' during the Depression. She remembers their house as cold and damp. At the age of 11 she was evacuated to the countryside, although even here the danger of bombs frequently forced her to sleep in a 'shelter' – a damp cave. At the age of 14 she returned to London, began work in a hosiery factory, and started to smoke about five cigarettes per day. Her work in the factory involved either winding silk, which was soaked in paraffin and gave off fumes, or winding cotton, which gave off dust; she does not remember there being any extractor fans. Her chest, which had improved somewhat since childhood, once again began to give her trouble, and she was first told that she had bronchitis at age 21.

At age 24 she stopped work, married, and moved into a house which was seriously damp, its roof having been damaged during the war, and 'repaired' with leaking corrugated iron. Mr E was an unskilled worker, so that his earnings were both low and insecure. His work also exposed him to unemployment (building trade), industrial disease (oil dermatitis in engineering) and excessive overtime (railway porter). The Es had two children and, whenever childcare allowed, Mrs E returned to a series of part-time jobs, one of which exposed her to soldering fumes (coil winder in a TV factory) and another to dust (warehouse packer). Her cigarette consumption increased to 20 a day when aged 24, and continued at this level for 28 years until she was 52, when she stopped smoking altogether.

Mrs E's life seems to have begun to improve in the 1960s. When she was 31 she

finally moved into a new flat, although even here black mould frequently appeared on the inside walls of the hall, the living room and one bedroom. When she was 38, and her children 11 and 9 respectively, Mr E obtained a clerical job (BR booking clerk) which for the first time gave him a secure income, although when she was 56 he was forced to take early retirement.
Nothing about this life history throws doubt on the role of tobacco. Nevertheless, it is noteworthy that many of Mrs E's environmental, residential and occupational hazard exposures, as well as her childhood and adult chest disease, preceded her heavy tobacco smoking."

Re-reading for the first time in more than 15 years my account of Mrs E, I am struck by the interest and potential of a biographical approach to disease aetiology. Unfortunately, I made the mistake of sharing my work first with a group of British and Swedish medical sociologists, who with the exception of Hilary Graham seemed so patronising and dismissive that I lost heart and put the work aside for nearly a decade. In retrospect, when I think of those involved, I realise that I was too thin-skinned. Their lack of enthusiasm was probably nothing more than the old *keep off my patch*-reflex; plus, perhaps, the political timidity of a relatively new and, at the time, somewhat marginal discipline. Nevertheless, looking back, I can see that since then I have preferred to work with social epidemiologists.

My spirits returned when I met George Davey Smith who introduced me to the idea of academic work as a blood sport. Before meeting George I had written two peer-reviewed journal articles; after meeting George, together with Mel Bartley and Chris Power, I started to churn them out. It was one of the most creative phases of my academic life, and a time when collectively we did much basic thinking. Around this time Michael Marmot, Richard Wilkinson and John Fox founded the International Centre for Health and Society, which has proved an equally long lasting influence on my work, not least by introducing me to health inequality researchers from the European mainland and North America.[4] Also, I started working with Jerry Morris on the education dimension of health inequalities, collaborating over time with Ian White, Tarani Chandola and Paul Clarke. Collectively, these intellectual and research collaborations overcame the isolation of being the only academic social scientist in my medical school.

The policy context was also moving in my direction. By the mid-1990s the civil service started to make tentative contingency plans for life under a future Labour Government. Labour, in opposition, had rallied to the *Black Report*, and, perhaps in anticipation that this interest would continue into government, the Department of Health somewhat at arm's length produced a report on social variations in health (the then obligatory euphemism for social class differences in health) which concluded: *It is likely that cumulative differential exposure to*

health damaging or health promoting physical and social environments is the main explanation for observed variations in health and life expectancy (Variations Sub-Group of the Chief Medical Officer's Health of the Nation Working Group, 1995, p.1). At the same time, the charitable sector, in the shape of The King's Fund, took up the issue of health inequalities, through which Sir Donald Acheson refreshed his interest in the topic, an interest that developed further when he became Chair of the International Centre for Health and Society. Also, the Economic and Social Research Council funded a research programme on health variations, under the directorship of Hilary Graham, which awarded me my first research funds to investigate social class differences in health.

My study design drew on three elements of my past. From George Brown and his colleague Tirrel Harris I took the idea of using a comparatively small-scale study, and methods which combine the quantitative and qualitative approaches, to investigate the social causation and distribution of disease. From George Davey Smith and his colleagues Stephen Frankel and David Gunnell I took the idea of epidemiologic archaeology, by which I mean resuscitating a long forgotten survey of a population's health. And from my time at Forest Road I took the idea of the life course accumulation of hazard exposures and the lifegrid methodology. From these sources came our analyses of contextual and life course influences in a stratified random sample of the Boyd Orr cohort. The members of the sample had been surveyed first, as children, by Sir John Boyd Orr in 1937–38, and many expressed shock when we re-contacted them some sixty years later (*I feel as though Big Brother has been watching me all my life* was one comment). They were interviewed by Lee Berney and Paula Holland. Guided by Michael Wadsworth's advice, I have maintained contact with the members of this stratified random sample, who have helped me by volunteering their participation in several further studies. In many ways, the cumulative impact of the data they have supplied has been a major influence on the development of my thinking about inequalities in health. For example, life course processes are discussed in terms of accumulation, critical periods and pathways, often with the implication that these models represent competing alternatives. Our Boyd Orr analyses, in contrast, have shown that critical period, accumulation and critical period-accumulation interaction can all occur in the life course development of a single disease outcome.

Midway through the ESRC Health Variations Programme, the Labour Party won the 1997 general election. Among its first actions was establishing an Independent Inquiry into Inequalities in Health, under Donald Acheson's direction. Members of the Inquiry's key Scientific Advisory Group included Hilary Graham (who was directing the ESRC Programme), Michael Marmot (who was Director of the International Centre for Health and Society) and Margaret Whitehead (who had co-authored the earlier King's Fund volume on health

inequalities (Benzeval *et al.*, 1995); and who, with Frances Drever, the Inquiry's Statistical Adviser, had co-authored the recently published 1991 Decennial Supplement (Drever and Whitehead, 1997)). Richard Wilkinson, George Davey Smith and I were among those commissioned by the Inquiry to write input papers (Gordon *et al.*, 1999). Donald Acheson's report of the Inquiry's findings was published in 1998 (Acheson *et al.*, 1998), to praise and acceptance from the government, but reservations from some health inequality researchers, such as Jerry Morris and Peter Townsend, who were critical of the report's failure to prioritise a relatively small number of costed recommendations for action. When challenged on this point in the newsletter of the Faculty of Public Health Medicine, Donald Acheson said he intended to monitor the implementation across government departments of his report's many and wide-ranging recommendations.

The potential impact of such implementations was illustrated the following year by Richard Mitchell and his colleagues Daniel Dorling and Mary Shaw (Mitchell *et al.*, 2000), who estimated that more than half of the excess deaths in parliamentary constituencies with above-average premature mortality rates would be saved by the combined effect on the most disadvantaged members of the working class of three policy initiatives. These were: reducing inequalities in income and wealth to their 1983 levels (saving 7,500 deaths per year); achieving full employment, to a situation where no one required long-term unemployment benefit (saving 2,500 deaths per year); and eradicating child poverty (saving 1,400 deaths per year). Of these three policies, Richard Mitchell drew attention to the large effect consequent on the redistribution of income and wealth.

As well as funding Richard Mitchell, Joseph Rowntree Foundation monies also enabled Donald Acheson to keep his promise to monitor government implementation of his report's recommendations. Working with Michael Marmot, Mark Exworthy and Marian Stewart, he found that most departments, encouraged by The Treasury, were planning initiatives designed to implement the report recommendations that applied to them (Exworthy *et al.*, 2003a). Donald Acheson welcomed the central lead given by The Treasury; and the targets for reducing health inequalities that were adopted by the Department of Health. Working as part of this research group, I found myself asking repeatedly *...but has anything changed on the ground?* What Mark Exworthy's expertise as a social policy analyst slowly made clear was the contradiction between the Labour Government's commitment to reducing health inequalities and its stronger commitment to other, countervailing, policies (Exworthy *et al.*, 2003b). First among these was its commitment to stay initially within the previous Conservative Government's spending plans. This meant that few funds were available during the Labour Government's first term in office, and that any initiatives were

restricted to areas where disadvantage was most concentrated (health action zones, neighbourhood renewal schemes and so forth). Unfortunately, most people in poverty live outside these areas. Second was its commitment to such neo-liberal economic policies as low taxes, targeted benefits, and workfare, which meant that any redistribution of income and wealth was surreptitious and small-scale, falling far short of the levels indicated as necessary by the work of Richard Mitchell and his colleagues. Third was the Government's commitment to local autonomy, which stymied centrally funded initiatives, in favour of centrally set targets which local authorities and health trusts were expected to achieve within their existing budget constraints. Unfortunately for health inequalities, as Mark Exworthy and Lee Berney discovered in an earlier study (Exworthy *et al.*, 2002), health inequalities came low down the list of local priorities (in the words of one NHS manager *...people lose their jobs over waiting lists, not health inequalities*). Mark Exworthy and Marian Stewart favoured a moratorium on new initiatives that required local borough and health authorities to bid for special funds, and instead advocated mainstream funding, along the lines of the health service's Resource Allocation Working Party, to pay for initiatives designed to reduce health inequalities, such as Sure Start, free school fruit and nutritionally and educationally upgraded school meals.

Uncertainty over the direction of policy in relation to health inequalities is mirrored by uncertainty about whether social class differences in health currently are widening or no longer widening or starting to reduce. Alissia Goodman's work at the Institute of Fiscal Studies suggests that income inequalities have stopped widening, apart from the incomes of the richest one per cent of the population, which are increasing exponentially. David Gordon's work at the Townsend Centre for the Study of Poverty suggests that any reduction in child poverty has left untouched those families in greatest poverty. Christopher White at the Office for National Statistics and Madhavi Bajekal at the National Centre for Social Research suggest that health inequalities have stopped widening and may be narrowing, evidence which Daniel Dorling questions on methodological grounds.[5] So, no grounds for complacency, and certainly no grounds for thinking that the issues surrounding social class differences in health have been solved.

Conclusion

My involvement with health inequalities over the past 30 years has been an unusual experience in many ways. Social class differences in health have gone from being an embarrassing academic footnote to a major policy concern of central government, local authorities and the various professions within medical care. Researchers from many academic disciplines (economics, epidemiology,

demography, geography, medical sociology, medical statistics, medicine, public health, psychology, social policy) have collaborated to make scientific progress by eliminating many of the potential explanations for these inequalities, thereby allowing policy makers to concentrate on those areas where initiatives are most likely to be effective. These are real achievements.

Among future challenges, I suspect, are genetics, behaviour, impact assessment and the on-going need for good science. There will be a temptation, if health inequality targets are not fulfilled, for this failure to be blamed on weak science, which under-estimated previously the contribution of genetic differences to social class differences in health. Any such attempt to resuscitate eugenics and replay Sir John Brotherstone's 1975 Galton Lecture will need to be answered by the type of clear thinking shown by the authors of the *Black Report*. Second will be an attempt to limit any consideration of health inequalities to issues of health-related behaviours, like tobacco smoking and leisure-time physical exercise. It will be necessary to remind policy makers of the limited success of the 1980s' health behaviour intervention studies, and of the Whitehall I and MRFIT (Davey Smith *et al.*, 1996) estimates of the contribution of behavioural risk factors to inequalities in health. Third will be an on-going need to remind those in public health that health inequality impact assessment is not the same as health impact assessment, and that failure to make the distinction can lead to policies which widen health inequalities. Donald Acheson's favourite example of the latter is tobacco smoking, where current and past smoking cessation initiatives have been more effective among the more affluent sections of the population, so unintentionally widening inequalities in health. Finally, there is the question of how to ensure that health inequalities remain high up the policy agenda, and that effective policies are implemented centrally and locally. Citizens can make many type of contribution to this aim, but researchers uniquely can ensure that debate is based on good science. British researchers are enormously fortunate in having access to an unparalleled richness of longitudinal and birth cohort data. All we need to do is keep on delivering the goods.

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Notes

1 Worrying because the discrepancy raised the possibility that social class differences in health could be, wholly or in part, a methodological artefact of social class being reported and recorded differently at census and at death; a problem with the catchy title of numerator-denominator bias

2 It may be worth recalling that Brotherstone's lecture was in honour of Francis Galton, who coined the term 'eugenics', and that the lecture was published in a Eugenics Society volume.

3 In fact, as I learned later, the two are related intellectually in the sense that John Fox, when writing the Supplement, had consulted closely with Jerry Morris.

4 Those involved are too numerous to name, but Johannes Siegrist, Lisa Berkman and Johan Mackenbach have been particularly influential, not least by epitomising national differences in the form of health inequalities research.

5 Much of the evidence referred to in this paragraph was presented at the International Centre for Health and Society. *National Science Week Public Lecture 2004: what is happening to inequalities?* University College London, 15th March 2004.

3

In sickness and in health: working in medical sociology

Mike Bury

Introduction

Periodisation is a rather ugly word, if it is one at all. Yet, how should periods of time be divided up, whether historical or biographical? Sometimes the answer is to use a binary divide; before and after an event (before the war and after the war, before the death of a loved one and after it). As will become clear later, this particular approach has coloured my work on illness experience. Sometimes other kinds of category are invoked to handle biography and time, with far less logic but with resonance nonetheless. The most obvious of these is the use of decades. As I write, Tony Blair, like Margaret Thatcher before him, is berating the 1960s as a decade of woeful liberalism, if not libertarianism. Many of the ills of today, apparently, can be traced back to the 1960s. Too many rights and too few responsibilities. At one time, for Labour, the target was the 1980s, when it suited them to have Thatcher's legacy in their sights. Whatever one's view, however, decades seem to summon up the zeitgeist of a period, giving it shape and meaning. This is the case even if, as with the end of a century and the beginning of another, the dates themselves are merely arbitrary breaks in the passage of time.

In this chapter, I will also use decades, though largely for a more mundane reason; simply to help organise the points about sociology and health that I want to make. As will become readily apparent, the decades in question rarely fit the facts in any neat way. Perhaps this is as it should be.

I could begin with the 1960s myself, and with the sense of the world changing, and life as a sociology student at Sussex University changing with it. But as far as research is concerned, sociology at that time at Sussex, and in the UK more generally, was rarely interested in health, illness, or medicine. Its main preoccupations were with topics such as social class and religion. The former fitted in with Marxian, or, rather, Fabian trends in British social thought, and the latter drew heavily on Durkhiem's work on religion and social integration. The lasting legacies of Marx, Durkheim and Weber dominated our studies. Equally attractive, though, at Sussex, was the more understated but charismatic influence of a young philosophy lecturer, Istvan Meszaros, who ran (packed out) Monday afternoon lectures and whole courses on the 'Modern European Mind'. In these sessions Lukacs, Sartre and other luminaries in sociology, literature and philosophy were introduced and explicated. Mezaros seemed to know everything and everyone (though, unlike most of us at the time, was modest with it) inviting many of those he knew to speak at his guest lectures, and to stay on afterwards to talk to students. Tea with Habermas sticks in the mind as a high point of an egalitarian and intellectually exciting atmosphere that Meszaros helped to create – though I can see that name-dropping as well as difficulties of periodisation is a hazard in this kind of exercise.

But there was little or no interest in health or illness. American sociology had already established a track record in the subject, but even there it was not really part of the mainstream. Though Goffman's (1963a; b) work in the 1960s on mental asylums and stigma was influential, it was not taken as a part of a growing sub-discipline of medical sociology, let alone health services research. Scull's (1977; 1979) later work on the history of psychiatry, perhaps, had more impact on psychiatric thought. For other leading sociologists health did not figure in their work at all. When, for example C. Wright Mills (1970), made the famous distinction between 'personal troubles' and 'public issues' as being at the centre of the 'sociological imagination', he had in mind topics such as war, marriage and unemployment. The intersection of biography and history might be the crucial meeting point for the sociological imagination, but it was inevitably selective. Illness, especially physical illness, was widely seen as purely biological and medical, with little to add to the examination of contemporary social structures or cultures. This was to change rapidly in the 1970s.

From anti-psychiatry to medical dominance – the 1970s

The question of mental illness and the asylum is, perhaps, a good starting point in thinking about the transition from the 1960s to the 1970s, at least from my vantage point. In the UK, as well as in the US, problems associated with large-scale psychiatric hospitals were to the fore. Whilst they may have been designed with some form of 'asylum' in mind, offering shelter and protection for the mentally ill, such hospitals were seen as places where people were shut away. They were out of sight and largely out of mind. Hospital inspectorates were in existence, but they seem to have made little impact on the overall pattern of care. Huge daunting hospitals lay outside London and other major cities. In most of the vacations during my undergraduate years, I worked as a nursing assistant in an acute psychiatric admission ward in Brighton General Hospital (I have to pinch myself when I remember it was called 'H Block') and often ferried patients to larger hospitals in the area. Like all the other nurses, I helped remove and lock away patients' clothes when they were admitted, so that they could be returned in stages, as they 'responded to treatment'. Thus, humanity as well as sanity was recovered in small doses.

This was a heady time in psychiatry. Not only were mental hospitals being routinely criticised for inhuman practices, but wholesale onslaughts were being mounted on what Szasz (1961) called 'institutional psychiatry'. For Szasz mental illness was not *real* illness, but a more or less convenient way of excluding those whose behaviour was unacceptable. The rights and humanity of affected individuals, he argued, were being systematically denied. Whilst psychiatrists such as Ronald Laing in the UK were developing their own form of

'anti-psychiatry' movement, other, more sociologically informed voices were coming to the fore. In the US Thomas Scheff (1972) debated with Walter Gove (1970) the merits and demerits of deviancy theory as a way of understanding the labelling and subsequent 'career' of the mental patient. For Scheff, mental illness was a form of 'residual deviance'; a label applied to 'residual rule breakers' that other labels did not fit. For Gove such 'societal reaction' was less evident in empirical studies of what actually lay behind the labelling and hospitalisation of the mentally ill.

Other voices in Britain, too, were signalled what they took to be an overly romantic view of mental illness in much of the deviancy perspective, and fought for a view that such illnesses were real enough, as forms of suffering and distress; to both self and others (Sedgwick, 1982). The lamentable record of psychiatric treatment could not obscure the intractable and difficult problems to which it related. This view had considerable attraction to me, as a student of sociology who has been involved (albeit intermittently) in the care of acute psychiatric patients.

Of course the relationship of academic debate to social or policy change is debatable. Scandal and media coverage has probably more effect, and more to answer for. In the late 1960s and early 1970s a number of scandals erupted in the mental health field in the UK, especially in what was then known as mental subnormality, or mental retardation in the US. These terms transmuted into mental handicap in the years that followed, and then more recently into 'learning disability'. In 1971 a research assistant post in the Mental Health Department at Bristol University was advertised. This had arisen from a government inquiry into a small mental subnormality hospital just outside Bristol, where patients had died at the hands of their nurses. Prison sentences and an enquiry followed. One of the recommendations made was for research into life on the wards at this hospital. During the first year of this three-year post, I spent ten months immersed in field-work (being supervised by the anthropologist, Vieda Skultans, and working increasingly closely with the psychiatrist Oliver Russell).

Again, the relationship between British and American social science was instructive in carrying out this project. Outside, (and to be honest, inside) psychiatry, mental handicap in the UK was a neglected area. Scandal may have raised its profile, but otherwise few were interested, and even fewer cared to know. In Britain, however, a small number of social scientists *were* interested, and wrote widely on the subject. Their interest was more policy oriented than theoretical, but it represented a sustained 'health services' orientation to the care of patients and the growing move towards community care. It was not long before the work of Peter Townsend (Professor of Social Policy in Bristol at the time) and especially Kathleen Jones (1975) was beginning to shape growing community care policies. Other workers in the field were exploring the

implications of such policies for the mentally handicapped, and the alternative 'therapeutic communities' that were being developed (Alaszewski, 1985).

All this had a big impact on me as a young researcher, in its combination of a 'feet on the ground' approach, and a sense of social justice. But the attractions of American sociology were present even in this neglected field. It has to be remembered that academic sociology, let alone medical sociology, appeared much later on the stage in the UK than in the US. In the US sociology had been alive and kicking in the late 19th and early 20th century. In the UK anthropology, as well as social policy and administration, dominated until the 1960s. Anthropology's focus on small scale societies and on meticulous field work (detailed observation and recording of rites and customs, and the learning of local languages) seemed suited to studying remote places. Its relevance to modern societies was, perhaps, less evident, and might help explain its relative decline, especially in comparison to sociology's rising popularity.

But when I read the US anthropologist Robert Edgerton's (1967) book, *The Cloak of Competence: Stigma in the Lives of the Mentally Retarded*, I realised that the dividing line between anthropology and sociology could often be weak. For here was a book looking at mental handicap, not simply as a policy issue and as a cause for concern, but, sociologically, as a lived experience. Here were the mentally handicapped (the US term 'retarded', then and now, grates too much) portrayed as living out their lives, using artful tactics to 'pass as normal' in local settings, and dealing with the stigma that could be seen to characterise their fate. People were seen attempting to display social competence, and sometimes succeeding, and trying to fashion a quality of life that was sustainable. Without such a perspective it seemed to me that health and health care issues would be dominated by policy debate, with the people involved visible only in the background, if at all. The sociological imagination could not, surely, deny the importance of policy and politics. But an interpretative approach to interview and observational data, gathered from the field in question, could make a distinctive and sometimes poignant contribution to our understanding. That I tried to do (Bury, 1974).

Towards the end of the three-year post in Bristol I became aware of other sociologists working in the health field, and not just in mental health. The British Sociological Association had set up a medical sociology study group, and was holding a conference once a year. For some reason one of the first (I think the very first was held in Blackpool) was held in Weston-super-Mare, not far from Bristol. Irving Zola, professor at Brandeis University, was the guest plenary speaker. Severely disabled through polio and a later traffic accident, Zola had directed his sociological imagination towards a wider range of medical targets than psychiatry. He took on what he saw as the increasing medicalisation of society, and examined issues such as the cultural variations in illness experience. Zola

(1972) also examined the social processes that helped explain how people turned into patients. At the conference and afterwards I realised that groups of sociologists were working in cities such as Aberdeen and Swansea, as well as in London, on a number of similar topics. Survey work on everyday illnesses, lay responses and the use of services (Wadsworth *et al.*, 1971), or on the doctor-patient relationship (Cartwright, 1967) was being supplemented by studies using more qualitative and observational methods on what was going on in clinics and hospitals (Stimson and Webb, 1975; Strong, 1979). The influence of Freidson's (1970) critique of the power of medicine, or 'medical dominance', effectively to marginalise the lay world and experience of the patient could be seen in much of this emerging work.

In 1975 I decided to leave Bristol and take up a post as a research sociologist in an epidemiology unit concerned with the rheumatic diseases (funded by the Arthritis and Rheumatism Council (ARC)) based in the medical school at Manchester. Although the kind of more general health related work, alluded to above, was appearing with greater regularity, it seemed strange to many of those around me that I should be planning to work in the field of arthritis. What, exactly, did arthritis have to do with sociology? Could the intersection of biography and social structure usefully be examined in such an arena? I was in some doubt myself. But the confidence and enthusiasm of my new senior colleague, the epidemiologist and rheumatologist, Philip Wood, was enough to persuade me. In Manchester, I soon found out there were people in departments of anthropology, psychiatry, social medicine, the history of medicine (especially John Pickstone) and others (though almost none in the rank and file of the sociology department, apart from Peter Worsley) who had a wide range of interests in health and medicine. Lunchtime seminars in the medical school drew people from near and far, exchanging views and research findings on a host of – to me – new and exciting areas concerning social aspects of health and medicine.

Working with Philip Wood gave me the freedom to develop research of my own, alongside the continuing concerns of the ARC Unit. Perhaps a key example of both can illustrate the atmosphere and changing research agenda of the period. As far as my own research was concerned I spent a good deal of time learning about arthritis and rheumatism and observing clinical care in the rheumatology department of the Manchester Royal Infirmary. Having presented myself to one of the senior consultants, and having explained (at too great a length no doubt) what my interests were, he simply said if I wanted to hang around his clinic that was fine with him. I did just that, talking to patients in the waiting rooms, in the clinics themselves and following the usual troop of doctors on ward rounds. No doubt, today, a thousand forms and ethical committees would have to be dealt with in order to undertake such observations, but I don't think I did any harm, and I learned a great deal.

In due course I began interviewing patients about their illnesses in a more sys-tematic way, and set up a series of home interviews of those attending the clinic. These were women and a few men suffering from rheumatoid arthritis. Doubts about the interplay of biography and the wider social environment, in undertak-ing such a study of illness experience, soon evaporated. Perhaps the best way to convey what I mean here is to recall one of the interviews I carried out. As many an interviewer will tell you, false memory notwithstanding, the details of some interviews stay with you for the rest of your life.

This particular interview was with a young mother living in a relatively poor district of Manchester. I turned up at about teatime. Tea was on the go. Although she was married, the woman's husband was often away from home for long periods. He was doing two jobs, end on, I was told, just to make other ends meet. The woman's arthritis was aggressive and painful, and was adding consid-erably to an already stressful life. Before the interview had been going for few minutes the front door opened, and a small child entered, carrying a tin of beans. The child offered the tin up to the woman to be opened. I asked why she couldn't lend the child the opener. She looked at me without saying anything, and I felt the foolishness rise in my face. If the neighbour didn't have an opener of her own it was not likely she would return one lent. As the interview proceeded I learned more about life in the house. Not only did the woman have two children of her own to contend with, but others in the area plagued her, and not just with borrowing. Youngsters on bikes would ride into her garden and annoy her through the front windows. Petty crime was rife. One day, she told me, her television had been stolen. Later the same week she was coming home and saw a blue light flash-ing in the upstairs front room of her next-door neighbour. She was convinced that it was her television in the room. A bad lot, the next door neighbours. The woman said nothing to her husband. She was alone all day and had no one on hand to help. On top of it all, the arthritis had set in, following an incident where she had ended up having to carry one of her children home from school.

In this short summary the interplay between personal troubles and public issues seems evident. Illness from this viewpoint is clearly not just a biological event, but a social one too, reflecting and feeding into the resources available and the context in which it occurs. For this woman, as for so many I interviewed at that time, illness was a seriously disruptive event. Whatever the circumstances, the onset of a seriously disruptive chronic disorder is likely to have long lasting effects – what I was soon to call 'biographical disruption' (Bury, 1982). But it was undoubtedly shaped by the social position of the individual affected, whether in terms of the reaction of others and the interactional strains it occa-sioned, or the material effects it had on income and household expenditure. Whilst clinical medicine could try to treat the symptoms of the woman's disease, only wider public health and social interventions could make a difference to her

quality of life. A safe, secure and supportive neighbourhood is good for everyone, but especially those affected by long standing illness. Here, in my interviews, I could see the relevance of sociological studies of chronic disorders carried out by Anselm Strauss (1975) and his colleagues, in which the personal difficulties of patients were seen at the same time to pose serious challenges to the health care systems and public health policy. Though such ideas now seem almost commonplace, they were not at the time.

Similarly, in the field of disability, a number of moves were afoot, to clarify and revise received approaches. One such initiative focussed on Philip Wood's international work, especially with the WHO. For Wood, the problem arose from the limitations that were becoming ever more evident in the traditional medical model of disease, and in the classification systems related to it. The International Classification of Disease, for example, dealt largely with systems of the body (in the case of rheumatic diseases, with 'diseases of the muscular-skeletal system'). But for Wood, from his epidemiological perspective, and for me and my colleague, Lisa Badley, it was the *consequences* of disease that mattered, as much as their causes. This was especially true with conditions such as rheumatism and arthritis, which, like so many chronic disorders did not lend themselves to any primary prevention strategy. Epidemiological research as well as practical public health responses, we argued, needed to be based on different premises. Throughout the late 1970s we worked many a late night and on many revisions of a new system which came to be called the International Classification of Impairments Disabilities and Handicaps, published by the WHO, as a supplement to the ICD in 1980 (WHO, 1980). A revised version was published in 2001 as the International Classification of Functioning, Disability and Health.

Debates about disability, including opposition from disability activists to these schemes, began as soon as they appeared. These focussed on how far existing academic research reinforced an individualistic, not to say medicalised view of disability. From this perspective disability was a product of discrimination and the 'oppression' of individuals with various impairments. From my viewpoint, such an argument led to an 'oversocialised' view of disability, and detracted from examining the many complex relays between illness, impairment and disability (Bury, 1997). But there was little doubt that chronic illness and disability were emerging as major features of both a renewed public health medicine and an emerging medical sociology. Debates about disability and illness coloured my publications over the next few years, as I moved once again, this time to London.

Chronic illness, disability and the 1980s

If the 1960s and 1970s were decades of change and the development of new ways of thinking about health and medicine (in this account at least) the 1980s

were more about retrenchment and consolidation – a form of periodisation used to characterise developments at this time (Gabe *et al.*, 1991). In public health the very different critiques of modern medicine developed by McKeown and Cochrane (let alone the polemics of Illich) as well as sociological studies in the 1970s, were beginning to be reflected in health policy. I have suggested elsewhere that research on prevention and the views of lay people in the community refocused attention outside hospital (Bury, 1997). The era of medical dominance and the all-powerful hospital had perhaps reached its peak and was beginning to decline. The new approach to health and illness outside of the clinic reflected changes in the wider (medical) culture. Important studies by Mildred Blaxter and others provided key insights into lay thinking about health, and the influence of upon it of different social contexts (Blaxter, 1983; Pill and Stott, 1982). With the development of HIV/Aids in 1981/82 a combination of public health epidemiology and medical sociology set out to tackle a major preventative challenge. Colleagues in sociology were immediately recruited to the task, and despite Margaret Thatcher's disdain for the subject, large sums of research monies flowed into the area.

For my own part, I had moved to London in 1980 to take up a lecturing post with Margot Jefferys, one of the founder members of medical sociology in Britain (Jefferys, 1978). She, along with George Brown, had set up the Social Research Unit, in the Sociology Department at the then Bedford College (later to be merged with another University of London college, Royal Holloway, at Egham in Surrey). My move to London meant, initially, occupying a large front office on the first floor of 51 Harley Street, rented by Bedford College for a peppercorn rent. If this location and its rental seem strange, I ought to mention, perhaps, that the Anti-Vivisection League had offices on the ground floor (attracting huge piles of mail, seemingly full of cheques) and thus few doctors wanted to be there. Walks to the main College in Regent's Park were along Marylebone High Street, and past some of the most expensive real estate to be found anywhere in Britain. Later, we moved into Bedford College premises in Regent's Park itself. Taking our sandwich lunches in one of the most beautiful parks in the world, Margot and I would sit and discuss medicine, politics, university life, as well as gossip.

Work did go on as well. I found that alongside Margot Jefferys' research activities on the changing character of general practice and primary care (Jefferys and Sachs, 1983), my interests in chronic illness and disability fitted in well. They also chimed in with work being conducted by Jon Gabe and his colleagues in the Unit on the management of 'minor' psychiatric disorders in the community, and especially the use of the benzodiazepine tranquillisers. Chronic illness was being studied independently by Betsy Thom. I began in earnest to try to write up my interview data gathered in Manchester and to think more systematically

about other chronic disorders and their relationship to disability issues. This gave rise to a number of collaborations and publications in the years to come, especially on 'biographical disruption' and the family context of chronic illness (Bury, 1982; Anderson and Bury, 1988).

In late 1981, however, I faced disruption in my own life, falling ill with a lung infection, thought at the time to be TB. It wasn't, but the symptoms were pretty close. Unsurprisingly, a degree of panic ensued all round, including at Bedford College. In the event, Margot and other colleagues there proved to be the best one could have wished for, making the necessary changes while I was laid up, and supporting me when I began to recover; albeit with complications which took a number of years and more stays in hospital than I care to remember. Of course, as common sense as well as research would tell you, it was family life that suffered most, with my wife battling to keep her job going as a teacher, and maintaining family life with our two young daughters. This was not an easy time. But I also recall, at one point in my 'illness trajectory', lying in a hospital bed next to a young sheet metal worker who was there to have a heart valve repaired. He constantly watched the door of the ward at visiting times in case his boss arrived to tell him that his job was finished. Though I was loathe to make sociological observations at the time (like anyone else, my main preoccupation was getting well, and back to normal life) his illness was clearly hedged about with fears of long term difficulties stemming as much from his social situation as from his medical condition. Support at home and at work made all the difference to my own recovery.

Getting back at work after a number of months away was helped by the appearance of some of my work in print – the only time when the inordinate delay in getting anything published (even when accepted) seemed to work in my favour. Margot Jefferys was moving into retirement, and colleagues and I were planning to keep the London University Master's course in Sociology with Special Reference to Medicine (a key feature of the Unit's life) alive after her departure. Ray Fitzpatrick, and then Mary Ann Elston (appointed after Ray's departure to Oxford) continued to be associated with the course in the years that followed. In 1988 Mary Ann and I decided to move our activities to Egham, where our main department had been relocated.

At that time, my and Margot's research interests began to overlap more closely. These focussed particularly on ageing and social gerontology. My own work on chronic illness and disability had frequently touched on matters to do with ageing, but I had not focussed on it as sufficiently as I might have done. Although many forms of chronic illness affect younger people, these tend to be the rarer conditions. In general, the 'epidemiologic transition' of low death rates and a rise in degenerative and chronic disorders was part and parcel of a 'demographic transition' towards an ageing society. It is somewhat strange to talk now

of an 'ageing society'. During the 1980s the phrase was on everyone's lips, and there was much wailing and gnashing of teeth about the 'time bomb' about to hit society. On her retirement Margot had directed an ESRC programme on studies on ageing and had written (with Pat Thane) that the alarm being expressed about the growing numbers of the elderly, and especially the very old, reflected the continuation of deep-seated ambivalence toward old age in society (Jefferys and Thane, 1989). Today, despite the continuation of such ambivalence, the acceptance that most societies are and will remain much older in their demographic structure than in the past is more in evidence. Now, the talk of pensions and health and social care takes on a new momentum. The 'ageing society' has clearly arrived and we must get on and live with it.

What Margot and I wanted to know in the 1980s, was more about what life was like at very advanced ages. The numbers of those aged 85 and over, and especially centenarians, was rising particularly quickly. Again, medical correlates of old age, and social policies to meet people's needs were crucial topics, but little first hand data were available on the everyday life of the very old. Indeed, statements from leading commentators on ageing such as Peter Laslett (1989) were rather dismissive of those in the 'fourth age'; they faced little more than decline, decrepitude and death. As with my other work, I wanted to know more of what was going on 'from below'. During the mid 1980s Margot introduced me to Sir Cyril Clark, then at the Royal College of Physicians, and Anthea Holme, a long standing colleague and friend of Margot's. Through a number of meetings we were able to agree on a research protocol for a national study of health and quality of life of those aged ninety and over, living in England. Sir Cyril helped to secure the funds, and Anthea joined me as the key researcher on the project. We then set out to survey 'life after ninety' (Bury and Holme, 1991).

Two main findings of the survey are perhaps worth noting at this point, as they touch on lasting concerns in the field of ageing studies; or 'studies about ageing' as I should properly put it. The first concerns the question of diversity in later life. Despite Laslett's negative depiction of the 'oldest old', we found considerable heterogeneity in health, disability and circumstance in our sample. Much depended, as in early life (but perhaps more so), on the availability of family support and, especially, good quality accommodation. As leading commentators in the US have argued, despite the obvious hazards of growing old we should not presume that a given age group is characterised by particular attributes (Suzman *et al.*, 1992). We found many people remaining active as well as inactive, and we were not always sure how incompatible the latter was with a good quality of life.

Second, our study reinforced a long-standing feeling (call it prejudice if you will) that public health medicine's preoccupation with mortality was increasingly missing the point. A continuing emphasis on reducing early deaths, important

though this was (as I could testify personally) had the inevitable effect that, as a measure of public health, mortality rates became less important. Donald Patrick (1986) pointed this out clearly at the time. What this meant, from my viewpoint, was that a shift in emphasis was needed in both epidemiology and medical sociology. Despite the considerable body of work available in social gerontology and related policy analysis, little work on the topic was being carried out by medical sociologists, with notable exceptions (Arber and Ginn, 1991). Yet, as Irving Zola (1991) was pointing out in the US, disability in later life meant that few of us could avoid it in the long run. Disability was a growing feature of the health profiles of late modern cultures that did not fit neatly into the boxes of our existing thought. This view also challenged the more divisive wing of the younger disability activists, whose call for political rights seemed to ignore the complex needs of an ageing population.

Critique and application – the 1990s and beyond

By the early 1990s medical sociology was firmly re-established at the new base of Royal Holloway. Mary Ann Elston, Jon Gabe and myself, were teaching on the medical sociology Master's and carrying out a number of research projects. We also had the good fortune of having Raymond Lee teaching research methods on the Master's course. By this time I had also been appointed to a personal chair at the University of London, and *Life After Ninety* had appeared, written by Anthea Holme and myself. Later in the decade Jon, Mary Ann and I took on the editorship of the journal *Sociology of Health and Illness*, in a happy and productive collaboration, which helped us keep up with and possibly shape the field during the period. I also took over from my close colleague, Gavin Drewry, Professor of Public Administration, as head of my department. Quite why is another story altogether.

In the health care field more generally, the 1990s was marked by the appearance of the first of a raft of initiatives, which, even now at the time of writing in 2004, shows no sign of slowing down. As ever, medical sociology research, nationally as well as locally tended to reflect the dominant agenda; now that of governmental rather than medical interests.

Then, as now, the political watchword was 'reform', soon to be followed and combined with 'modernisation'. As Raymond Lee noted in our conversations at the time, the word 'reform' (like 'freedom', 'liberty' and most irritatingly, 'choice') could only make one smile. For him in particular, 'reform' always brought to mind his Catholic schooling in Northern Ireland, where the history teacher would speak of the 'so-called' Reformation. In the NHS since the early 1990s so-called reforms have been legion, and some of them have even brought benefits to patients and staff. In the main, however, they have constituted a

continuation of the ethos instituted by Thatcher; the attempt to move the NHS from a provider led service to one which is more patient oriented, or as we now say, marked more by 'partnership' – another of those rhetorical words.

Social science involvement in these reforms can be seen at a number of levels. Perhaps two examples can help to illustrate briefly the kind of issue being pursued, at least in my own research back yard. The first concerns the growth of evaluation in health services. The legacy of the 1970s has certainly been important in one key respect, at least, namely the growth of Cochrane inspired initiatives to expose medical interventions to systematic study, especially through RCTs. As Sir Richard Doll (1998) has pointed out, it was independent clinical judgement that held sway during the early years of the NHS, and beyond. The growth of evaluative research was heralded as the beginning of 'evidence based practice', where clinical decisions would be related to the best possible research evidence about the outcomes of treatment.

In the main, medical researchers have held that the RCT is the gold standard of evaluative research. Yet even Cochrane saw that RCTs are not always feasible or ethical (in some forms of life saving surgery, for example, where random allocation would be impossible). The generalisability of many RCT findings to clinical practice in real communities is also more limited than is generally recognised. Moreover, public health research can rarely perform experiments on large populations groups, for example, by making people redundant to examine the effects of unemployment (Marmot, 2004). Epidemiological research is necessarily often descriptive and observational in character, examining patterns and their possible determinants, rather than conducting trials.

At Royal Holloway Jon Gabe and I were carrying out research which often touched on issues which were the subject of debates about clinical effectiveness, but to which we added a further dimension. For example, I have already mentioned the controversy surrounding the use of benzodiazepine tranquillisers, which continued throughout the late 1980s and early 1990s. Argument raged about whether the evidence from trials and clinical practice showed that these drugs were addictive, either physically or psychologically. What interested us, however, was the way the whole area had become one of intense public concern, and how different players – patients, doctors, pharmaceutical companies, mass media – were shaping its emergence. We were trying to 'figure out what was going on', to paraphrase the anthropologist Clifford Geertz. We paid particular attention to the circumstances surrounding the dramatic withdrawal of a benzodiazepine hypnotic from the market in 1991, and the charges of malfeasance and libel which followed. In writing up the story, including the libel hearings that took place at the Old Bailey, we were brought into conflict with the company ourselves and almost landed up in court (Gabe and Bury, 1996).

In areas closer to my interests in chronic illness, research funded by the

Department of Health allowed us, in the mid 1990s, to explore the meanings attached to childhood asthma, which then, as now, was regarded as taking on epidemic proportions. I was, and am, doubtful of these claims about the 'epidemic' of asthma, if only because like so many areas of health and health care, such a disorder is open to 'risk amplification'. This often involves over prescribing, over diagnosis, over treatment and medicalisation of normally occurring low-level symptoms. At worst, it threatens to draw attention and resources away from the more severe end of an illness spectrum to the wider 'worried well', or to the 'worried not-so-ill'. Our qualitative interviewing of children with diagnosed moderate or severe asthma showed, as other social research had done, that many young people did not regard their illness as serious or life threatening, and had well worked out strategies for dealing with any crisis that might arise (Gabe *et al.*, 2002). Whilst not wanting to detract from the need for urgent intervention in severe cases, the research acted as a warning against the adoption of blanket approaches to complex socio-medical issues. Our more recent work on developing 'partnership' in health care with children has struck a similarly cautionary note about 'one size-fits-all' health policies issued from above (Gabe *et al.*, 2004). In reality, partnership and shared decision making may suit some patients and not others. It may have particular limits with specific groups of patients, such as children or vulnerable older people. In any event a critical if positive view needs to be taken of the dominant 'discourse' circulating in official health care circles.

At the heart of sociological reasoning lies its desire to take a step back from the immediate pressures of events and headlines, and to look beneath the surface, or at the least to set the issues involved in their wider social and political context. This, of course, can be irritating if the story that unfolds does not confirm the 'assumptive worlds' of those involved (this time the words are from among the favourites that Margot Jefferys used to invoke). Irritation can also be caused if the sociologist strikes an arrogant or disrespectful, rather than a truly 'critical' note. The sociological imagination needs to be independent of vested interests, but it also needs to realise that it is also part of the world it seeks to examine. Often, critiques which see health and medicine 'merely' as social constructions, or the conspiracy of professionals against the laity, do an injustice to the actual worlds that patients and their carers (professional or lay) inhabit.

Today, as the new millennium itself unfolds (how *that* word has so quickly come and gone from our lexicon) terms such as the 'patient's perspective' or 'self-management' in chronic illness continue to figure strongly in government thinking and policies for the future of health care (Department of Health, 2004). For me, as I now contemplate the rise of chronic disease to near the top of the health policy agenda (alongside continuing concern with inequalities and new dilemmas such as obesity) the sociological imagination seems to be needed as much as ever.

However, a sense of irony will not be lost on anyone who has watched the development of medical sociology over the last thirty years. For, having called for greater attention to the patient's viewpoint, and to the deleterious effects of 'medical dominance', we now see government departments incorporating such ideas into official documents and plans. The patient's view becomes transformed into self-care and self-management, and medical dominance turns out to be no more than unwarranted and outdated paternalism. Under these circumstances, the two-fold approach of medical sociology, now in its 'mature industry' phase perhaps, will be needed as much as ever – trying to interpret the significance of such developments for the wider society, and trying to use its theories and research methods to make a contribution to improved understanding. At the least it will need to see health as a dynamic process, influenced by many factors (Bury, 2005). As I move into early retirement, the field seems as lively, critical and important as ever. And if recent textbooks are anything to go by, the sociological study of health and illness has finally entered the mainstream.

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4

Random assignments: my route into health policy: A post-hoc rationalisation

Anna Coote

Health research was not at the forefront of my mind when I entered university in the mid-sixties. I had a hazy idea that I might be a writer of some kind but I never really decided – then or since – what I wanted to be when I grew up. So I cannot describe my career in terms of rational planning, only as an accretion of experiences and lessons learned along the way.

The two most useful things I can remember learning at Edinburgh University, apart from brief encounters with moral philosophy and 20th century European history and politics, came from beyond the faculty. The first was to scrutinise my sources. A fellow student picked up a course book I was reading and asked me what possible reason I could have for believing a word the author had written. I had gotten all the way to higher education without imagining that I shouldn't believe everything I read in text books. I began to learn that knowledge is constructed – not least by the interests and perspectives of academic writers.

The second was that the pen was mightier than I thought. Although I was officially studying Modern History and Politics, I spent much time working on the student newspaper, imaginatively entitled *Student*. In 1968, in my term as editor, *Student* issued a challenge to the university Rector (an elected post, intended to represent the students on the University Board), demanding that he support the students' views or resign. The students had elected Malcolm Muggeridge as Rector, thinking he was still the Angry Young Man he had once been, but by then he had grown into a Grumpy Old Man with an obvious distaste for students and all their disgraceful 1960s ways. So we published our irreverent demand, a harmless gibe we thought, and to our astonishment the old boy did resign, using the pulpit of St Giles Cathedral to denounce us all as degenerates and scoundrels.

There was not much else going on that week and it became a bit of a media cause celebre (revolting students and all that), not just in Britain, but even abroad. The *Washington Post* asked me to write an article explaining the students' case, which it published alongside one from the ex-Rector. This turned out to be my passport to employment. But there was another unintended consequence of the wee drama. After Muggeridge's downfall, the students won the right to elect one of their own number as Rector – and this honour passed to a young Gordon Brown. So it was that, thanks to the *Student* reprobates, our Chancellor took the first step of his political career.

I fled Edinburgh, as soon as I had my degree, for a job in Fleet Street on the *Observer,* thanks in part to that clipping from the *Washington Post* in my otherwise scanty portfolio. I wrote for the consumer pages at first, boldly revealing the advantages of new household gadgets, cosmetics, furniture and fashions. I graduated to the diary, Pendennis, where I interviewed countless celebrities including Oliver Reed, who got me drunk in Wimbledon, and Tom Courtenay, who was more courteous. I went to Paris to cover fashion week and report on the

'trendiest' night spots. Eventually I began writing magazine features and went to Rome to interview Fellini.

What did I learn from all this? Research techniques of a kind: how to pick up the phone and fearlessly ask an expert anything I didn't know; how to find the right people to ask by fearlessly phoning others. The craft of distillation: how to cram the fruits of an hour-long interview into 250 or even 50 words. How to use language so that every one of those words worked hard for its living. And introductory courses in (a) relations between commerce and consumer journalism and (b) the potent role of celebrity in contemporary story-telling.

At the same time, the new women's liberation movement was making its presence felt. First I reported on it, then I joined it. With my new-found feminism came a firming up of my campaigning zeal, which had gone to flab in the early *Observer* days. I began to write less about underwear design and more about social issues. In 1971 I produced a long piece for the front page of the *Observer Review* entitled 'The Underprivileged Majority'. It was the first major article on a feminist theme published by the *Observer*. The then editor, David Astor, called me into his office and told me, in his charmingly avuncular fashion, that I had got it all wrong – boys and girls *naturally* behaved differently, my dear, that was simply the way the world was. In the best tradition of editorial freedom, however, he let me have my say in print.

I wrote a book on civil liberties, which was published by Penguin in 1972 as *Civil Liberties, the NCCL Guide* (Coote and Grant, 1972). My co-author, Larry Grant, was the legal officer of the National Council for Civil Liberties (now called Liberty). We set out to produce an accessible guide to all aspects of citizens' rights. He and others drafted the legal material. I helped translate it into lay terms and researched some of the sections, including those on welfare rights. I was on a very steep learning curve. I began to find out about civil liberties and law, and – through trial and error – how hard it was to strike an elegant balance between forensic precision and easy reading. The *NCCL Guide* went into several editions and became part of a new trend in publishing popular guides.

Shortly before my publishing debut, I found that my now rather serious turn of mind had failed to impress a new editor on the *Observer's* features pages. I was made redundant in 1971 and joined an 'alternative' weekly newspaper called *Ink,* just launched by Richard Neville, hippie icon and editor of *Oz* magazine. *Oz* was on trial for obscenity at the time, thanks to some wonderfully smutty material in an issue co-edited by teenagers, and one of my jobs was to cover the court hearings at the Old Bailey. I watched John Mortimer defend the *Schoolkids' Oz*, in a colourful joust between the crème of London's cool and an utterly perplexed establishment. It was a sumptuous piece of legal theatre, on which I practised the darker arts of partisan journalism. *Ink* was great fun but it didn't break even. Just as the money ran out I was invited to write feature articles

for the *Evening Standard*. This seemed highly lucrative at the time and drew me into freelance journalism, which kept the wolf from the door for most of the Seventies.

While journalism paid the rent, most of my energies went into political activities around the NCCL and the women's movement. It seemed an inevitable step from writing a guide to civil liberties to writing one on women's rights. I had fallen in with a group of young lawyers, civil libertarians and trade unionists involved with the NCCL, many of whom became lifelong friends. I teamed up with one of them, a solicitor called Tess Gill, to write *Women's Rights: A Practical Guide*, first published by Penguin in 1974 (Coote and Gill, 1974). Technically, it presented the same kind of challenge as the civil liberties guide, but for me this was also part of a life-changing experience.

It seemed – although this was not quite true – that we were cataloguing injustices against women for the first time. As we researched the field and produced chapter after chapter on issues such as work, pay, maternity leave, training, tax, benefits, pensions, marriage, separation, divorce, children, abortion, rape, housing and so forth, we were discovering just how far the odds were stacked against women and how much needed to change. We were determined that women should overcome their 'oppression' (as we put it in those unselfconscious days). And for a few years it felt as though articulating a problem and helping to create and campaign for a solution was enough to change the world.

With others, including Tess Gill, Harriet Harman, Patricia Hewitt, Christine Jackson and Ruth Lister, I formed the NCCL Women's Rights Group, which became a focal point for much intense activity through the 1970s. We worked with MP Jo Richardson to change the law and get better rights for women – a new Sex Discrimination Act, new laws on rape and domestic violence, new pensions legislation, equal pay. We produced pamphlets, drafted bills, campaigned and lobbied. Each time we prepared a new edition of the *Women's Rights* guide, it had to be substantially revised because things were changing so fast. When the Sex Discrimination Act came into force, Tess Gill and I took El Vino, a ludicrous Fleet Street wine bar, to court for refusing to let women buy drinks at the bar. Our victory in the Court of Appeal contributed to the early case law on sex discrimination.

Meanwhile, throughout the 1970s, I wrote articles about women's issues in just about every available organ, from the *Sun* and *Cosmopolitan* to the *Guardian* and the *Sunday Times*. I co-founded another group, the Women's Report Collective which produced a news magazine for women that lasted for a decade. In the National Union of Journalists I helped set up the first Equality Working Party and wrote, in 1977, a pamphlet called *Images of Women: Guidelines for promoting equality through journalism* (NUJ Equality Working Party, 1977), which inveighed against the overt sexism of the press.

None of this, however, begins to sum up the vibrancy of the time. It felt as though we were inventing a new politics and, although we encountered huge resistance, we could also see that attitudes and practices were changing. We were naming problems and concepts that had not, it seemed, been named until then: domestic violence, sexual harassment, a 'woman's right to choose' to control her own fertility, the 'personal is political', patriarchy, sexism, etc. We held sit downs and workshops and demonstrations, giving voice to anger and exasperation about imbalances of power, injustices against women, and men's attitudes and behaviour.

There were great debates among feminists too, and these demanded just as much energy and engagement. Was capitalism or culture to blame for women's predicament? Were men the 'enemy' or was it the patriarchal system? Were women complicit in their subordination? Could middle class women seek to liberate themselves without deepening the disadvantages of poor and black women? Should we give priority to law reform and public policy, or to changing what happened in our own bedrooms and kitchens? Was gender identity a product of nature or nurture? And so on. Books began to pour out into a brand new feminist market place. There were not yet any university courses in women's studies, but we were making them up as we went along.

What did I learn from this phase of my life? Experiencing a political movement in its primitive phase, I drew some pretty naïve conclusions. For a while I honestly did think that one only needed to point out to men the error of their ways in order for them to change, so strong was the force of our arguments. As the 1970s wore on, I learned to be more reflective, and to get a stronger historical perspective on what we were doing – finding, for example, that a 'women's revolution' was not unique to the 1970s, but occurred every half-century or so. This was helped by working with Beatrix Campbell on a contemporary account of the women's liberation movement, *Sweet Freedom*, published in 1982 (Coote and Campbell, 1982).

Throughout this period I ingested a huge amount of detail about feminist politics and women's rights – through straightforward desk research, interviews with experts and dialogue with peers in a wide range of forums. I took in some political and social theory, some sociology and psychology. I learned about different kinds of inequality, about political lobbying, about building the case for an alternative (a legal reform, for example) and how to follow it through on to the statute books. I began to understand about networks and power relations – and how, in various settings, they could be experienced as a positive or negative influence. I learned to look beyond the dominant discourse to find causes and arguments that were being overlooked or suppressed – and to find out why this was happening. Later, I learned to look for conflicts of interest between different social and economic groups and to understand passive resistance and how

powerful groups adopted this strategy to defend their interests and the *status quo*.

The 1970s were a time of galloping inflation, but this was not reflected in rates for freelance journalists. By 1978 I was starved out of the freelance market and had to look for a proper job. I went to the *New Statesman*, where I became Deputy Editor. In the following four years I took another crash course, this time in left-wing political journalism and all the hot topics of those years. Cruise missiles and the cold war, the resurgence of disarmament politics led by E.P. Thompson's passionate writings, the discovery of Cambodia's 'killing fields', the 'winter of discontent', the 'alternative economic strategy', Margaret Thatcher's arrival in Downing Street, and the post-Marxist critique of Labour by Stuart Hall, Eric Hobsbawm and others. An affable young barrister called Tony Blair turned up in my office, offering to write about legal matters and I edited his first published pieces.

In spite of my rather feeble efforts and others' good intentions, the culture of the *New Statesman* remained intractably masculine. It was a hothouse for up and coming writers and journalists – mostly young men. I felt I habitually represented a counter-cultural view that my colleagues regarded as marginal. This was never openly discussed, although I had some good-natured disputes about what constituted 'news'. There were only two kinds of news story, the editor Bruce Page would insist: 'We name the guilty men' and 'Arrow points to the defective part'. In other words, the only journalism worth the name consisted, in Page's view, of investigation leading to revelation of facts that others, usually mighty corporations, would rather keep secret. I argued against this 'Gradgrind' absolutism, in defence of more nuanced writing about human and political relationships, and began to reflect more closely on media values, their origins and the social and economic factors underpinning them.

I learned a lot more about writing, editing and commissioning. I also became more aware of the kind of 'story' that appealed to me. This occupied a space between factual reporting on the one hand, and opinion or polemic on the other. It involved searching out missing components of mainstream events and narratives, listening to different voices, especially the voices of disadvantage, and using research-based argument to reveal what had been hidden or overlooked. Notes from the margins that involved a critique of how marginal status came about. This was, I can see now, an 'outsider' rather than 'insider' perspective – one that has stayed with me all my working life.

In 1982 I moved on to work for a new company called Diverse, making programmes for Channel Four television, due to launch later that year. I was completely new to television, so had to learn on the job, which was editing a weekly current affairs programme called *The Friday Alternative*. This aimed to challenge the conventions of corporate broadcasting and (as we used to say with mock grandeur) 're-write the grammar of the medium'. It was highly irreverent

and anarchic, and nothing quite like it had been seen on TV before. But it was either too good or not good enough (probably the latter), to last more than a year. We turned to another format, with a new series called *Diverse Reports*. This produced personally authored, partisan current affairs programmes, achieving 'balance' for the regulators by inviting individuals of different political persuasions to be the presenter each week. The idea was to challenge the notion of 'objective' reporting by making it plain that everybody had a point of view.

I co-edited the series with a colleague called Peter Clarke, who had been an adviser to Enoch Powell and was a strong proponent of right wing libertarian politics and free-market economics. We shared a small office and luckily he was a good-humoured man. We argued our way through the early 1980s, including the Falklands War, the miners' strike and Greenham Common, and through these conversations and the programmes we made, I was privileged with another crash course – this time on the history and ideas of the 'new right'.

As well as adding to my political education and learning about television, I discovered how hard it is to explore ideas in this medium. Television production values abhor complexity and nuance, and anything that does not have pictures attached. News and current affairs values abhor uncertainty and consensus, and anything that takes too long to explain. Valiant efforts have been made by many programme makers and sometimes they have partly succeeded. But it is a struggle that offers few rewards.

Later I did some on-screen reporting, produced a documentary series for Diverse on the UN Decade for Women, had a baby, and took a career break. In 1987, I worked briefly as a columnist for the ill-fated *News on Sunday* (this is the bit of my career that tends to get air-brushed out of my CV). *NoS* was a doomed attempt by well-meaning middle-class lefties to produce a right-on tabloid for the masses. I learned that producing a successful tabloid newspaper requires a very particular set of skills and attitudes that most of us lacked. I also learned that one should not take life-changing decisions just after giving birth (especially with your first child). The experience is so miraculous, you may readily fool yourself that other miracles are possible. I sold my house and moved to Manchester to work for *NoS*, only to face redundancy when the money ran out after six months.

Back in London later that year, without a job or a house, I was just a little relieved to land a contract to produce a four part documentary series for Channel Four on the political left in Europe. We flew all over Western Europe (this was before the fall of the Berlin Wall) interviewing intellectuals, policy makers and political leaders. The modernisation of post war welfare states, shifting social identities and the emergence of environmental politics featured strongly. Again, I was on a very steep learning curve. We had to grapple with a range of complex and shifting ideas and try to make them compelling and visual.

Next Left, as the series was called, came out in early 1988. It met with favourable reviews and swift oblivion, as European politics began to change in ways we had neither dared nor been commissioned to imagine. Fortuitously, though, it provided a route into my next job.

For me, television and parenthood made an excruciating combination. In TV, you work in a team with a large budget, a mountain to climb and a very tight schedule: the culture is all-consuming. My daughter was not yet two. Plus, I hated going cap in hand to the commissioning editors at Channel Four, begging them to accept my ideas and give me another contract; it made me feel like a parish indigent and a double-glazing salesman rolled into one.

In between things, I had been writing a book with Polly Pattullo called *Power and Prejudice,* on how and why women sometimes succeeded and often failed to participate effectively in politics (Coote and Pattullo, 1990). It gave me a chance to learn more about patterns of resistance, catalysts for change and how opportunities can arise out of historically determined as well as random factors, and often from an interplay of both (class, education, networks, relationships, haphazard occurrences, timely interventions and so forth). It came out in 1990, when books about women for non-academic audiences were going seriously out of style, and hit the remaindered bins with lightening speed. I have never regained my appetite for writing books for mainstream publishers.

In the summer of 1988, I was approached by a new think-tank called the Institute for Public Policy Research. They needed someone to develop their work on the welfare state. Hadn't I just produced a major TV series on welfare politics in Europe? That was how I became a policy analyst.

IPPR had no money to pay me a salary, but offered me a modest fee to develop a work programme and encouraged me to fundraise. Thanks to early support from the Joseph Rowntree Foundation and the King's Fund, I began to develop IPPR's social policy programme.

Over the next decade at IPPR I worked in four main policy areas: gender and family; inequalities, health and social policy; citizen participation; and media and communications. I learned about the world of think-tanks and how to operate in that setting, and was enchanted – and grateful – to find myself in such a stimulating political and intellectual environment. As a bonus, it was far better suited than TV production to the rhythm and demands of family life.

When I started out at IPPR there were only three others in the office: James Cornford as Director, Patricia Hewitt as Deputy and Jane Franklin as administrator. We were shortly joined by David Miliband and gradually we grew, taking in an economist, a human rights specialist and many other bright young people. If the *New Statesman* was a literary hothouse, this was a political one, though somewhat less macho, at least in the early years. Many of IPPR's researchers and associates went on to be political advisers, MPs and peers.

There had never before been a left-of-centre think tank quite like this in the UK, although Demos and the Fabians soon came close. We drew some inspiration from James Callaghan's Central Policy Review Staff, and picked up clues from Brookings in the US and from right-wing bodies such as the Adam Smith Institute. But there weren't many useful precedents for building and refining the processes in which we were engaged – research, analysis, policy development, and inside-track influencing – and fitting them together in ways that suited the UK context of the day. So we had to invent ourselves as we went about trying to re-invent left-of-centre politics, at a time when John Major led the Conservatives to their fourth successive election victory.

Just as in the early days of the women's movement, there was little time to reflect on that process of invention. We had to get on, come up with ideas and make an impact – and be seen to be doing so. IPPR led a hand-to-mouth existence. We had to raise funds for every project we undertook, so building the reputation of the organisation was all-important.

We needed well-tuned political antennae, to identify issues where we could usefully contribute new ideas, suggest practical changes and hope to get a positive reception among those who made decisions. Our main audiences were policy makers and opinion formers in and around the Labour Party, then in opposition.

We had to raise money wherever we could – from wealthy individuals, charitable trusts, trade unions, and the private sector. We did of course fervently defend our independence. But we also had to develop a sense of what kind of project was likely to attract funding – and where the gold was buried, as well as how to dig it up without being compromised. The fact that IPPR developed a strong strand of work in health policy was in no small part due to the willingness of the pharmaceutical sector to invest in a think-tank close to Labour.

We had to act fast and keep ahead of the curve. Politics is an impatient customer. Sometimes a major project would take 18 months, rarely longer than that, and often a great deal less. Once we had identified an issue, we had to imbibe as much relevant data as possible, brainstorm, analyse, distil and produce recommendations – all without losing momentum. That meant we rarely did primary research. More often, we acted as brokers between academia and politics. We worked with researchers, carrying out secondary analysis of existing findings. And we supplemented this with deliberation in workshops and seminars, with experts who were prepared to share their knowledge, helping us grapple with the issues and scrutinise our ideas. We had to be bold enough to cut to the chase, to forge recommendations that politicians could grasp and run with, and to cover our asses with defensible evidence.

We had to get media coverage. Lots of it, but in the right places. Even if we had a private line into a front-bench politician, our recommendations carried far

more weight if they were also reflected through the centre-folds of the quality broadsheets and flagship BBC news programmes. I didn't fully understand any of this at the time, but proceeded instinctively, hoping to learn from my mistakes.

My job, when I became a paid employee in 1989, was to develop ideas, raise money, engage researchers, analyse findings and see projects through to fruition, organise events and write or edit final reports. Health policy came up early as a hot political topic. The Conservative government was trying to introduce an internal market in health services; debates about service quality, funding and rationing were beginning to emerge. Where did the Left stand on these issues? IPPR's implicit mission was to get the Left off the defensive back foot and on to the offensive, leading the development of ideas for the future, rather than wallowing in nostalgia for the 'good old days'.

How to do this? Sometimes it helped to go back to first principles, looking behind the dominant narrative to find a fresh perspective and work through the practical implications for public policy. Most of the debate, fired by the iconic status of the NHS, focused on the mechanics and economics of service delivery. I took to wondering what health policy was or should be for. Should it just be about treating and curing the sick or should it also – even primarily – be about safeguarding the nation's health and well being? The answer seemed blindingly obvious to me and to many others, but how to improve health and reduce health inequalities was not part of the mainstream discourse on health policy. I became fascinated not only by what it might take to shift health policy towards tackling the underlying causes of illness, but also by why this was a marginal concern.

I drew encouragement from the work of Ken Judge, Bobbie Jacobson and Michaela Benzeval at the King's Fund, who were tending the flame lit by the *Black Report* (Black *et al.*, 1980) with their research into health inequalities. And by David Hunter, then Director of the Nuffield Institute, under whose guidance I worked through the case for giving priority to prevention, and with whom I co-authored *New Agenda for Health,* published by IPPR in 1996 (Coote and Hunter, 1996). This was to be a recurring theme for the next eight years.

On issues of quality and rationing of health services, I became interested in how decisions were made. Whose voices were heard and not heard? Who should be involved and how? This eventually led to our work on citizens' juries. At first it was just a phrase, describing a notion that interested people in IPPR circles: an interesting idea, but no-one knew what it entailed. I commissioned a researcher to find out where (if anywhere) such juries were operating and we located two centres – one in the US and one in Germany – where models had been developed that engaged ordinary citizens in deliberative decision-making about policy and planning. With John Stewart and Liz Kendall, I published a report in 1994, *Citizens' Juries* (Stewart *et al.*, 1994)*,* setting out proposals for

developing them in the UK. We were quite taken aback by the amount of interest this received – not only from the media, but also from local government and health service organisations all around the country.

We used the juries to test out ways of involving lay people in decisions about rationing health care. With a grant from the King's Fund we formed a partnership with Opinion Leader Research to pilot citizens' juries in three UK health authorities. This gave us a better understanding of the strengths and weaknesses of the model and helped us to develop a policy framework for informed, deliberative citizen participation in decision-making. It encouraged the development of a range of methods (workshops, forums, etc.) to suit different purposes. Other organisations began to experiment with citizens' juries and related models. With Jo Lenaghan I produced a second report, *Citizens' Juries: Theory into Practice* (Coote and Lenaghan, 1997)*,* published by IPPR in 1997. Our ideas about deliberative democracy helped inform other emerging debates at IPPR – on the politics of risk, for example.

For all my practice in distillation, I find it hard to distil the IPPR experience. Once, when the money ran out (again!), I spent two years (1991–93) as a senior lecturer in the Department of Media and Communications at Goldsmith's College, London University – my only brush with academic employment. I loved the students, but found the institutional life far less lively and stimulating, and raced back to IPPR to take up a Paul Hamlyn Fellowship and become Deputy Director.

IPPR allowed me to learn about public health, health inequalities and health service issues, about the development of public policy, about fundraising, commissioning and managing research, organising events, and about influencing techniques. I learned to work at the interface between ideas, research, communications and politics. I had a chance to explore connections between gender, family, community, health and well being, poverty and social justice, democracy and power – and the privilege of engaging with brainy, bold, creative colleagues.

In 1997, when Labour won the election, I was asked to advise the incoming Minister for Women, Harriet Harman, who was also Secretary of State for Social Security. I agreed to go in as a part-time consultant while I looked for a new job, as it felt like a good time to leave IPPR. I found myself taking yet another crash course, this one on the inner workings of Whitehall and what it's like for politicians to find themselves in government after almost a generation.

I also learned about the Downing Street courtier system: how everyone has to pay court to the Prime Minister through his inner circle of mainly young, white and male spin doctors and advisers, who – regardless of their varying levels of skill and knowledge – exercise total control over physical access to the main source of power, as well as the flow of ideas. Patrice Laconte's 1996 film *Ridicule* about patronage at the court of Louis XVI resonated strongly with my

experience of Number 10, as did my memories of importuning commissioning editors at Channel Four. But I wouldn't have missed the experience for anything, even though 'my' Minister was axed from the Cabinet in the first reshuffle. That, as they say, is another story.

Half way through my year in Whitehall I was hired by the King's Fund to head their new public health programme. I took up the post in August 1998. It felt like sailing into harbour after a storm. Here was an organisation with an august history and reputation, independence backed by a reasonably safe inheritance and an enviable track record in building knowledge about health inequalities. It offered the chance to develop a new strand of work, in a political environment that seemed wide open to influence. If there was ever a good time to help bring public health into the mainstream, this was surely it.

Unsurprisingly in retrospect, it was a lot harder than it appeared at first glance. We worked with Tessa Jowell on the development of the Green Paper, *Our Healthier Nation*, which seemed a useful starting point for a broad-based approach to preventing illness and reducing health inequalities (Department of Health, 1998). Then we watched with dismay as targets based on clinical conditions dragged the agenda back towards the medical model of health in the White Paper, *Saving Lives* (Department of Health, 1999). We had more success in London, where we lobbied to change the draft bill for the Greater London Authority so that the new mayor would have a duty (albeit a limited one) to promote the health of Londoners. And we worked with the NHS and local government to form a cross-sectoral partnership that became the London Health Commission.

I soon discovered that working for a heavyweight charity in a favourable climate did not make it much easier to change the political agenda. The public health 'community' had been on the defensive for years (this was reminiscent, to me, of the Labour Party in the late 1980s: always on the back foot, and perhaps reflecting historical links with the 'old' political left). Was there a fresh story to tell, or a lateral perspective, that would help bring public health into the heart of health policy making?

I began to wonder how much good – or harm – the NHS itself was doing to the nation's health. It was, after all, a huge institution, with a workforce comparable in scale to the Chinese army and the Indian railways. How far did it use its corporate power to improve health – through employment, purchasing, building, utilities management, and so forth? What could it do differently? If managers and clinicians could be encouraged to think in these terms, would they begin to pay more attention to the underlying causes of ill-health?

In 2000 I was appointed to the UK Sustainable Development Commission – another opportunity to learn by sudden immersion. I began to explore, with my King's Fund colleague Karen Jochelson, the synergies between health and

sustainable development, to gather and distil evidence about the impact on health of different kinds of corporate activity, and to work out the practical implications for the NHS. In 2002, the King's Fund published *Claiming the Health Dividend* (Coote, 2002), which set out the case for a health-promoting and sustainable use of NHS resources. It fell on fertile ground prepared by others such as Sue Atkinson, John Ashton and Robin Stott. It may not have brought prevention into the mainstream of health policy (that had to wait for Derek Wanless (2002)), but it did help shift thinking at the centre about how the NHS should behave as a corporate entity to promote health and sustainability.

Throughout that year and the next, the mainstream health policy agenda continued to be dominated by health service issues – waiting times, foundation hospitals, patient choice, clinicians' contracts, structural reorganisations and so forth. But there were always opportunities to shift the agenda if one looked beyond the mainstream. Early in 2000 I helped to form the Gender and Health Partnership. This brought together, for the first time, women's health organisations and feminist researchers with the Men's Health Forum and other campaigners and academics involved in the emerging men's health 'movement'. There had been some bitter rivalry between the men's and women's health groups over funding sources and media attention, but in fact they had a lot in common: trying to improve understanding of how gender shaped assumptions and patterns of behaviour that influenced health outcomes, health research and health care. We realised that more could be achieved by working together than by sparring from separate corners. Convening meetings at the King's Fund, we were able to promote new research and organise the first UK Gender and Health summit in 2003.

Late in 2002 I had a visit from Roger Harrabin, a leading reporter on the BBC's *Today* programme. He told me he had been tearing his hair out because, try as he might, he could not get stories about public health issues, as distinct from health services or health scares, past the editors and into the news bulletins. He was planning to take a three-month sabbatical at Green College, Oxford, to investigate the problem. For me, this was an important part of the jigsaw, as I had seen how closely politicians followed – and were influenced by – the news media. I arranged support for him to extend his sabbatical to six months and commissioned a media researcher, Jessica Allen, to carry out an analysis of health news reporting. This found, among much else, that there was an inverse correlation between the severity of risk presented by a health issue and the volume of news coverage it received. The more deaths, the fewer headlines and vice versa. Our report, *Health in the News,* was published in 2003 (Harrabin *et al.*, 2003): it helped to raise awareness, stimulate debate and generate some critical reflection in at least some parts of the news media.

It also became a springboard for a major new public health initiative at the

King's Fund, launched in 2004, entitled *Putting Health First*.[1] This started from the premise that a great deal was already known about the extent and causes of illness and health inequalities, and there was a growing body of evidence of the kinds of intervention that were likely to be effective in promoting better health and narrowing the health gap. There was also broad agreement that most forms of ill health were avoidable and that prevention was of the utmost importance. What was less well understood was why policy makers, opinion formers and health professionals continued to give priority to 'downstream' health service issues. The way conventional news values influenced policy makers was only one small part of the picture. What would it take to develop a health system that really did give priority to health? Whose interests were at stake, whose power was being threatened and how was change being resisted – passively or otherwise? *Putting Health First* was designed to explore a much wider range of issues, including public opinion, leadership, the form and functions of local health services, incentive structures and the role of evidence in policy and practice.

I developed a strong personal interest in the latter issue: how evidence and evaluation shaped – or failed to shape – policy and practice in the major social programmes of the Blair government that aimed at reducing health inequalities and ending social exclusion: Health Action Zones, Sure Start, New Deal for Communities and Neighbourhood Renewal. I was struck by the way the Blair government had embraced the idea of evidence-based decision making, or doing 'what works', apparently as an alternative to the value-based politics of left and right. At the same time it was investing in vast, national initiatives that were driven from the centre but that relied upon 'empowered' local people for implementation. How far was it possible to base them on evidence of 'what works', how could one find out whether they were themselves effective and, perhaps most important, what role did politics play in gathering, interpreting and deploying the evidence? I commissioned research in the UK as well as a series of international seminars, organised jointly with the Rockefeller Foundation and the Aspen Institute and produced with Jessica Allen and David Woodhead a report entitled *Finding Out 'What Works'*, which was to be my last publication for the King's Fund (Coote *et al.*, 2004).

When the second Wanless (2004) review was published in February 2004, it felt at last as though the margins of health policy could be shifting. Even the news media became interested in public health, with a sudden flurry of stories about obesity. Health Secretary John Reid announced a major consultation and promised a public health white paper later in the year. But was this a watershed or a temporary deviation? We still do not know.

Which brings me up to the present. This chapter was supposed to be about how and why I 'entered the broad area of health services research'. I have great respect for researchers and couldn't do my work without them. But, as you can

see, I am scarcely a researcher myself – certainly not a researcher of health serv-
ices. At various times I have passed muster as hack, writer, broadcaster,
pamphleteer, agitator, producer, commissioner, editor, lecturer, policy wonk,
analyst, ideas-broker and influencer. I have come this way through a combina-
tion of luck, opportunism, random occurrence, planning and graft. In 2005 I
moved from the King's Fund to the Healthcare Commission to lead their work
on engaging patients and the public – a chance to revive my interests in effec-
tive participation, deliberative dialogue and citizen-led decision-making. When
forced to reflect on my odd-ball career I take some comfort from complexity
theory. Who needs linear progression anyway?

Unsurprisingly, I would favour more cross-fertilisation between the worlds of
research, policy making and communications. However, that's a complicated
business. Few individuals can just hop across successfully from one field to
another. Each one has different values, different cultures, different skills. It took
me the best part of a decade to make the move from journalism to policy devel-
opment. During that time I gradually discovered how little I knew and how
much more I had to learn – not only about the policy issues themselves, but also
about the process. So I end where I began – beset by ignorance. Only now I
hope I know a bit more about it.

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Notes

1 http://www.kingsfund.org.uk/pdf/Healthfirstfactsheet.pdf

5

Last season's fruit

John Grimley Evans

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To the just-pausing Genius we remit
Our worn-out life and are – what we have been

Matthew Arnold

My earliest memories are of people dropping bombs on me. They missed – but only just. I was too young to understand what was going on, and it is only in much later life that I have come to suspect that the experience may have cast a subtle colouring over my attitude to the world. Conflict is a part of normal life, people can be gratuitously evil but there is a postwar world of peace and reconstruction to look forward to. Some day. Perhaps.

Like many other aspiring young doctors from underprivileged and non-medical families, I set out to be a surgeon. Certainly Alf Gunning and Harold Ellis provided Oxford clinical students with exhilarating role models. But six months hanging on to a retractor as a House Surgeon led to reconsideration. I was neurologically and psychologically unsuited to a career that depended on scrupulous accuracy in repeated manual procedures. Neurologically unsuited because defective coordination prevents my doing the same thing in the same way twice running (golf is an impossibility, and flyfishing hazardous to bystanders), and psychologically because of low tolerance for repetitive tasks.

Two years of junior hospital jobs with no official off-duty left me with a higher qualification in medicine but significant physical and mental debility. Consequent illness put me for a time on the receiving end of the National Health Service. The care was excellent but the experience redirected my perceptions of what medicine should be about. What matters in the immediacy of a patient's experience may not correspond with what carers see as important in a longer-term perspective on the future. This is only partly a matter of the patient perhaps having no rational perception of a future; it has to do with personal priorities that may not match those of his doctor or the dimensions of a generic measure of quality of life. It was also alarming to discover that illness can change such personal priorities and life view. Years later I was to become very irritable with the glib assumptions of the advance directive brigades. To whom was I as a doctor supposed to be responsible when caring for an older person with dementia or stroke – the patient in front of me, or the different person that patient might once have been? In arguing with the secure egos of the bourgeoisie it sometimes seemed that only people who had themselves suffered a significant illness were able to conceive that there might be a problem, that the "I" of yesterday might not be the "I" of today. It was equally difficult for secure egos to grasp that the "I" might not be one of "us".

Surgery was not alone as a potential career treadmill; specialisation in medicine also proffered daily rounds and common tasks. I already knew diabetes clinics as mentally paralysing; neurology in those pre-CT days seemed mostly headaches and speculation, and the stifling clouds of irritable bowel syndrome were already gathering over gastroenterology. Old-fashioned general medicine, with no claims to special expertise or fancy tests, offered infinite prospects of the invigoratingly unexpected – if approached with an open mind and an

enthusiasm for looking things up. Moreover, general medicine as taught in Oxford in the 1950s emphasised total and continuing responsibility for the welfare of individual patients; the job was not done until they were back at work or digging the allotment. But, we were constantly being told, general medicine as a career specialty was doomed. Colleagues assured me that general practice offered no shortage of the undiagnosed, and indeed undiagnosable, but without the time or resources for looking things up. Fortunately, most illnesses in primary care get better anyway.

But I enjoyed clinical medicine; it was what I had signed up for. So I needed some career in which a research interest could be developed in parallel with clinical activities. Exciting things were beginning to happen in immunology but I knew from A-level chemistry that laboratory glassware and I were less than symbiotic, and I found white rats lacking in charm. Happily, Fate played the first of three benevolent cards, and I fell into a post as Junior Research Assistant to Donald Acheson, then May Reader in Medicine in the Nuffield Department of Clinical Medicine (NDM). Professor Leslie Witts who presided over the Department was a shy and kindly man free of the studied eccentricities of some more celebrated contemporaries. Witts' interests and talents were also broader than most medical professors. The brilliant colleagues he had gathered round him won their spurs in gastroenterology and haematology, but his Department was also suffused with sensitivity to the social and public health context of medicine.

My work with Donald Acheson involved taking an interest in the Oxford Record Linkage Study (ORLS) that was just producing its first results and to analyse a ten-year set of incidence data on ulcerative colitis. The potential power of routine health service data, adequately cleaned and linked is obvious, if only from the formidable scientific productivity of the US Veterans and Medicare databases. It is shameful that the NHS has never managed to create a comprehensive linked system of health records. Nowadays it is easier to recognise that British governments are inevitably ambivalent about creating an objective set of data that might be used to catalogue the unglossed performance of the NHS. From the Körner reforms of 1985, NHS data became geared to the needs of accountants rather than of clinicians or medical scientists, in line presumably with government priorities. How much easier it would be to individualise the results of clinical trials if we had routine data that could be used to find out if, and to whom, the results of trials apply in real life (Soumerai *et al.*, 1997; Thiemann *et al.*, 2000).

I cut my epidemiological teeth on Donald Acheson's ulcerative colitis data, doing everything by hand and making every possible mistake along the way. I had acquired a smattering of statistics doing a Part 2 Natural Sciences Tripos in Psychology at Cambridge, but had never had responsibility for the minute study

of a dataset. With a fairly small number of cases it was essential to validate every data item. Two interesting features of the data for a budding epidemiologist were an apparent increase in incidence of ulcerative colitis over the decade studied and a double peak of high risk in early and again in later life. Could these findings be due to "ascertainment bias" (better diagnosis of the disease as the decade passed) or "denominator errors" (inaccuracies in the estimates of the population sizes at different ages) (Grimley Evans and Acheson, 1965)? The double peak in age-associated risk has been found in other and later data sets but still awaits a definitive explanation.

I used ORLS data, followed by visits with the future mother of my children to the rodent-infested and part-flooded cellars of the Radcliffe Infirmary, to retrieve case records for an incidence study of deliberate self-poisoning, then in its adolescence as an epidemic. This demonstrated an apparent seasonal association that more detailed analysis revealed as imitative behaviour, a phenomenon that has been rediscovered many times since (Grimley Evans, 1967). Despite their distinctive epidemiological patterns in terms of age and sex, the verbal linking of "attempted suicide" with "suicide" has continued to generate confusion in the media and even in more respectable circles. The observation that phenomena other than diseases can be illuminated by an epidemiological approach was to influence my later interest in ageing.

Oxford was one of the frontrunners in the use of the randomized controlled trial to evaluate new treatments. Especially prominent were the various steroid trials headed by Sidney Truelove in the Nuffield Department of Clinical Medicine. The close association of epidemiology and clinical trials in the department offered a valuable lesson, since widely forgotten, that the utility and generalizability of a clinical trial depends on the demonstrable epidemiological provenance of the patients enrolled. Epidemiological concern for the quality and relevance of data has come to play second and plaintive fiddle to an obsession with sample size. But what is the use of a precisely calculated "treatment effect" if clinicians have no idea what sort of patient it applies to? This is a continuing problem for clinicians working with older people who have not been represented adequately in clinical trials, on occasion, possibly, with seriously misleading consequences (Thiemann *et al.*, 2000).

Trials carried out in the NDM were scrupulously supervised, but elsewhere the rationale of randomization was not always recognised. There was a widespread assumption among non-numerate doctors that the aim of randomization was simply to ensure equal numbers in treatment and control groups. Clinicians were understandably anxious that critically ill patients should have at least the chance offered by a new treatment that might work, and reportedly "opaque" envelopes were held up to powerful lamps to decide whether a patient should be entered in a trial or not. Such was therapeutic enthusiasm at the time that the

possibility that a new treatment might do harm took some years to register fully. These problems with early clinical trials are relevant to systematic reviews. In later years, as Coordinating Editor for a Cochrane Group I came to suspect that unsatisfactory methods in clinical trials may have persisted longer in continental Europe than in the UK.

Donald Acheson was a first rate clinician, and emphasised the importance of epidemiology to clinical practice. It is obviously relevant to one's prior probabilities in the process of diagnosis; it is also relevant to the assessment of outcomes; what does it matter how brilliant one's treatment is if it has no perceptible effect on the prevalence or severity of the relevant disease in the community? It is still often necessary to explain to medical students and self-congratulatory doctors the difference between fatality and mortality rates (fatality is the proportion of patients with a disease who die from it over a specified period from onset or presentation; mortality the average proportion of the total population who die from the disease each year). It is perfectly possible for hospital fatality rates to fall without there being any discernible effect on mortality.

This was inspiring stuff. Thereafter my goal in life became work in some branch of clinical medicine where I could apply epidemiological principles to evaluation and improvement of services. At the time, a backlog of talented but ageing and frustrated senior registrars warned that general medicine might not prove a happy choice of career, and opportunities for linkage to epidemiological research rather than white rats seemed limited. What about psychiatry? The Cambridge Tripos had offered only minimal instruction in clinical psychology but the tutor, Russell Davis, had been impressive and enthusiastic. More importantly for my aim in life, the epidemiology of psychiatric disorders was advancing rapidly under the influence of Michael Shepherd and others. I headed off to a local asylum, bearing Jerry Morris's (1964) "Uses of Epidemiology" as a *vade mecum* from Donald Acheson. It is by me still.

An exploratory year as a Registrar in Psychiatry to the charismatic Felix Letemendia provided valuable clinical experience but exposed my unsuitability for the specialty. I had difficulty synthesising the various conflicting schools prevalent at the time. As Duty Doctor at the hospital I had to follow different policies according to which consultant was nominally in charge that night. This would determine whether a referred patient should be given chlorpromazine, inducted into group therapy, comforted and put to bed to "sleep on it", or simply turned away to meet government requirements for reducing mental hospital beds. The locked back wards of long-stay patients were daunting in their physical bleakness, but often revealed an unexpected warmth of human sympathy. Some of the male nurses were second and third generation employees at the hospital and treated their charges with friendly tolerance and affection. True, only the first edition of Barton's (3rd edition, 1976) "Institutional Neurosis" had

been published at the time, and even though I was responsible for the statutory annual physical examination of long-stay patients I may have missed signs of abuse, but I do not think so. But it was apparent that the back wards of the old asylums had functioned in part as oubliettes for the socially inconvenient. Things had to change.

More worrying was the outpatient work. In the catchment area was a large motor works, then locked in self-destructive conflict between militant shop stewards intent on bringing down the capitalist system and managers content to provoke strikes and disruption to cover their own incompetence. Caught in between were men driven by over-paced production lines and stressed by long hours and rigid cycles of shift work. Their wives struggled to keep up the hire purchase payments during strikes and layoffs while trying to raise children in a home with a father either at work or asleep. The resulting mental morbidity found its way to the local general practitioners and psychiatrists as depression and as the "simple neurosis" defined by Taylor and Chave (1964) in their study of New Town malaise. But it seemed something of a prostitution of medicine to connive in labelling as "ill" the casualties of a social system that ought not, in England in the 1960s, to have been regarded as acceptable.

Fate then played its second trump in the form of an advertisement for a Research Fellow in Clinical Epidemiology and Preventive Cardiology in the Medical Unit of Wellington Hospital New Zealand. I applied and after a memorable interview in his Richmond home with John Butterfield, was appointed. Ian Prior, Director of the Unit, was undertaking a series of studies of the health of Polynesian and European populations of the South West Pacific. The post offered a preliminary year of training in epidemiological field methods in the US and Europe. My first visit was to the World Health Organisation where Dr Zdenek Fejfar assured me "if you choose a career in epidemiology you will not make any money but you will meet the nicest people". He was correct on both counts. My next stop was with Jerry Morris and his team, who were doing seminal work on London busmen and on differential fatality rates in peripheral and central hospitals (there is nothing new under the sun). In the course of a delightful visit to Harry Keen and the Bedford Diabetes Study I was alerted to the unexpected in epidemiology – in one case an effect of a particular brand of jam in the lunchtime sandwiches on the accuracy of blood sugar measurements in the subsequent afternoon.

A wonderful year followed under the paternal tutelage of Fred Epstein in the Department of Epidemiology at the University of Michigan headed by Thomas Francis Jr. It was an exciting time in cardiovascular epidemiology as multiple logistic models were being developed and investigators wrestled with the problems in pooling data from different prospective studies. My chief task was to familiarize myself with the methodology of the Tecumseh Study so that we could

replicate it in community studies in the Pacific. It was an ideal model since although now best known for its contribution to cardiovascular epidemiology Tecumseh was a study of all aspects of the health of a total community. Even the household pets were included (Epstein, 1960; Napier, 1962).

The generosity of the University of Michigan and its staff to me and to other indigent foreigners studying there was outstanding. A useful general lesson for an aspiring academic was to recognise that the goodwill generated among foreign students by hospitable universities is a valuable invisible export for any developed country.

In addition to making myself a general nuisance by peering over people's shoulders and asking naïve questions at meetings I was able to audit courses on statistics and genetics and join ward rounds. Particularly memorable were J. V. Neel's seminars on his thrifty gene hypothesis (Neel, 1962). Through natural selection, populations who had been through severe periods of starvation would accumulate genes that enabled their bearers to lay down excess calories as fat that could then be called on during periods of famine. Neel suggested that in environments where calories were continuously in excess these "thrifty" genes would produce diabetes and other deleterious metabolic effects. This idea was to prove particularly relevant to work among Polynesians migrating from the subsistence economy of coral atolls to the affluence of urban New Zealand.

On the way back to Europe we spent a family week with Bill Miall and the MRC Epidemiology Unit in Jamaica, taking a particular interest in blood pressure studies. I then visited Archie Cochrane and the field teams in the Rhondda before a spell at the London School of Hygiene and Tropical Medicine undergoing training and standardisation by Geoffrey Rose in reading electrocardiograms and measuring blood pressure.

After this truly magnificent year of experience and training I arrived in New Zealand towards the end of 1967. Ian Prior had accumulated a large mass of data that needed working through and publishing and this provided my first task. The University of Wellington had one computer and it only read paper tape and insisted on being programmed in Algol. No relevant software was available so I spent many hours writing programmes to do very basic things such as calculating regression coefficients and inverting matrices. Almost invariably the paper tape would break at a crucial moment and many a time my precious printouts were scattered over the landscape as I turned the corner of the computer building in the aptly named Windy Wellington. But as with my time in Oxford I appreciated the value of working close to a dataset for spotting anomalies and patterns.

One of the stimuli to Ian Prior's work was the concern of the New Zealand Government over differences in mortality and morbidity rates between European and Maoris as revealed in national health statistics. Ian had started

with surveys of townships and villages of different racial composition and confirmed that indices of cardiovascular morbidity risk mirrored the health service data. The next step was to find how any genetic risk factors carried by native Polynesians could be affected by the physical and social environment. Surveys of Cook Islanders had already revealed striking differences between two communities, one on a volcanic island, Rarotonga, and the other on the coral atoll, Pukapuka. Particularly interesting were differences in blood pressure apparently associated with different salt intakes (Prior *et al.*, 1968). The Government was about to embark on a programme of encouraging Tokelau islanders to migrate to New Zealand and Ian Prior recognised a possible natural experiment to study the impact of environmental change on health through an incidence study (Prior *et al.*, 1974). The Tokelau Islands comprise three coral atolls some 300 miles north-west of Samoa. The islands each had populations of around 600, and being a New Zealand Protectorate, their inhabitants had rights of New Zealand entry and citizenship. Periodically the islands were flattened by hurricanes and their health and education services were difficult to support. Encouragement of migration to New Zealand therefore seemed a logical approach to the welfare of both islanders and New Zealand taxpayers, provided any detriment to health could be prevented.

As with Polynesia in general the Tokelaus had no malaria, but filariasis had been endemic before government eradication programmes, and many of the older islanders had varying degrees of elephantiasis. Coconut trees grew on the island but there was little soil for other vegetable crops and fishing provided the staple diet. It was taboo for fish to be left on the island overnight for the wandering spirits of the sea to find and take vengeance on the canoes the next day. If a shark were caught everyone on the island, including any passing epidemiologists, must partake so that the spirits could not smell out the fishermen actually responsible for the death of the creature. The main causes of premature deaths were accidents and drowning, but there was abundant cultural evidence of past troubles from wars and slave traders. Property, essentially coconut trees and houses, was inherited through the female line and, as a tradition from the days of trying to deceive slavers, boys were disguised as girls until puberty. With a diet consisting largely of fish and with a large output of calories in obtaining it, we were expecting to find that risk factors for cardiovascular disease to be uniformly low in the islands. The men were physically very fit and obesity occurred only among women and was at most moderate in degree.

In addition to epidemiological and medical expertise our team included two biochemists, a paediatrician, a nutritionist, a technician, and an anthropologist. The last was crucial since if any deleterious impact of life in New Zealand were to be detected the ways of mitigating it would be dependent on an understanding of the Tokelauan culture. One aspect of that culture was that decisions were

made by councils of older men on a basis of debate to unanimity. Our response rates were therefore going to be either 100% or zero. On one of the islands we were advised that opposition to our survey was coming from the local medicine man who felt his prestige was under threat from these visiting white doctors. Ian Prior promptly developed a painful back and asked the medicine man for treatment. This required Ian to lie lying prone on the sharp coral rubble while the medicine man walked up and down on him and the islanders looked on with interest. This public validation of our respect for the medicine man's skill won us our 100% response rate. The treatment must have worked too, because Ian never again complained of his back trouble while we were on the islands. Field epidemiologists will recognise the general lesson for enhancing response rates through identifying and disarming significant sources of opposition.

With the aid of the immigration authorities Ian's team was able to contact Tokelauans who subsequently migrated to New Zealand and follow their health status. As anticipated, risk factors for cardiovascular disease, and the prevalence of coronary heart disease had been low. Salt intakes and blood pressures had been intermediate between those previously found by the research team in Rarotonga and Pukapuka (Prior *et al.*, 1968). The impact of New Zealand life became apparent with astonishing rapidity. Cheap cigarettes and alcohol (encountered for the first time) produced their usual problems. Obesity bloomed as thrifty genes thrived in a bath of excess calories. Blood pressure, cholesterol, uric acid and glucose rose. Nothing surprising here in the light of Prior's previous prevalence studies, but to see the effects of environment and lifestyle taking place under one's very eyes was electrifying. I became intrigued by the implications for some of the doctrines absorbed in my student days, particularly with regard to the conceptualization of normality, ageing and disease. "Normality" had at least three different meanings – "common", "healthy" and Gaussian – and thinking slithered all too easily between them. There was no real reason why what was common should be healthy. Nor that it should follow a Gaussian distribution – was it really …'

was it really appropriate for a statistical distribution based on repeated measurements of the same object to be applied to the distribution of observations on a population of different people? Did it really make sense to specify a normal range of serum rhubarb, in such a way that the prevalence of hyperrhubarbaemia and hyporhubarbaemia were both automatically fixed at 2.5%? And surely when dealing with a continuously distributed risk factor such as blood pressure needing treatment with significant adverse effects, should not "hypertension" be defined as that level of blood pressure above which on average treatment does more good than harm (Grimley Evans and Rose, 1971)? This would allow hypertension at the population level to be designated according to the treatment currently available and in the case of an individual in the light of whatever other

risk factors are interacting. Most importantly, for my future career, was the realisation that the assumption that all age-associated changes represented the unfolding of an inexorable genetic programme was nonsense. "Correcting blood pressure for age" as had been widely taught was nonsense; blood pressure need not rise with age and if it does it is usually a Bad Thing.

My wife and I loved New Zealand and admired the New Zealanders, European and Maori, but the old career dilemma loomed again. Either I returned to clinical medicine (and white rats) or if I wanted to continue in epidemiology my future must be in public health (within a decade this changed and New Zealand has nurtured some world class epidemiological clinicians). I returned to the UK as Lecturer in Epidemiology in Donald Reid's department at the London School of Hygiene and Tropical Medicine, then as now one of the most exciting academic hothouses in the realm. Geoffrey Rose provided an ideal role model for an aspiring epidemiological clinician, but the waiting time for young doctors seeking part-time attachments to a London hospital approximated the national expectation of life at birth.

I began to consolidate an interest in age-associated disease and disability, with something of a sense of guilt at the way that my training in conventional epidemiological analysis was to start by "throwing away" age as a banal variable. This procedure was based on the assumption that age-associated changes are due to the ineluctable ticking of some kind of biological clock and therefore of no interest to the epidemiologist. But in biological terms, ageing is loss of adaptability of individual organisms as time passes, and the rate and pattern of that loss is determined by interactions between *extrinsic* factors in lifestyle and environment with *intrinsic* genetic factors. Real life data are complicated by additional cohort and survival effects compounded with the impact of ageist discrimination. Conventional medical thinking was also an impediment to rational analysis. In particular the traditional distinction between "normal ageing" and "disease" was no more than a futile attempt to separate the undefined from the indefinable (Grimley Evans, 1988). Donald Reid taught, very wisely, that epidemiological analysis should start with mortality, but the conventional assumption that mortality rates bore some straightforward relation to incidence could not hold in the study of ageing. Mortality rates are a composite of incidence and fatality, and ageing, being loss of adaptability, is associated with a general increase in fatality. It was also apparent that changes in diagnostic criteria and in therapy produced different effects on mortality in different age groups (Grimley Evans, 1971).

My primary interest was in stroke and blood pressure. It came to be generally accepted that in the UK stroke mortality rates had been falling for decades (Grimley Evans, 1986) and that this did in fact reflect a fall in incidence. What had been happening to blood pressure was much less clear. Clinical experience

suggested that malignant hypertension had become less common since the 1940s but discussion of this possibility revealed some curious traits in medical thinking. A few years earlier I had presented the data on the low and age-constant blood pressures of men in Pukapuka to some American clinicians. The only explanation they were prepared to countenance was survival artefact; in the absence of American physicians in Pukapuka, they asserted, anyone whose blood pressure rose would assuredly die and not appear in a prevalence study. British clinicians were equally confident in claiming that any decline in malignant hypertension must have been due to the high vigilance and clinical expertise deployed in general practice, even though what evidence there was suggested that malignant hypertension had started to diminish before effective therapy became widely available. But the notion that the relationship between the efficacy of treatments and the effectiveness of medical services might be complex was beginning to work through the system. A particularly forceful example for teaching purposes was to demonstrate that the hospitals with the lowest fatality rates for acute heart attacks were the ones with the slowest ambulance services; the more patients who had time to die in the ambulance, the fitter on average were those who survived long enough to appear in the hospital statistics.

Although there remained a need for epidemiologically minded clinicians, a career in academic social medicine now seemed the best option. But a danger, for some, of the purely academic life was exemplified by my growing absorption in the finding that blood pressure for both mothers and fathers fell by around 1 mm of mercury for every child they had had. Intriguing though this was (and counter-intuitive to a parent of young children), it was unlikely to be pertinent to the public health challenge presented by stroke in the UK. As I was musing one morning on my growing irrelevance, Fate played its third card. Ted Jarvis, an old student friend and first-class physician, telephoned and suggested that I should join him in developing a geriatrics service in Newcastle upon Tyne. Although the opening consisted of a NHS consultant post in geriatric and general medicine, it carried honorary university status and the social medicine departments in Newcastle were keen to have someone to help with the teaching of epidemiology.

A career in geriatrics was not something that I had ever countenanced; the teaching and role models offered in my student days had been deeply discouraging. But a visit to Newcastle was a revelation. The University was lively and responsive to new ideas and its Medical School was at the centre of medicine in the region. Regional hospitals hosted its students and regional consultants examined in its finals. The exclusiveness and arrogance that has estranged some other medical schools from their regions did not feature. With the commiserations and condolences of southern friends in our ears we moved north for the happiest years of my life.

Clinical practice among older people is a professionally rewarding career. However awful a patient's plight there is always something a multiprofessional team can do to improve things. Older people are often more interesting and usually more courteous than the young. The challenge of developing an effective geriatrics service in Newcastle was initially daunting. Over many years, older people who for one reason or another could not be discharged from acute hospitals had been placed permanently in long-stay beds in old workhouses, and when these were full, beds in the local sanatorium had been appropriated as the numbers of tuberculosis patients declined. There were approaching 400 beds in use and yet the geriatrics service had a waiting list of 120 and a waiting time of a year. Strenuous efforts supported by the hospital administration and the local social services department brought the situation under control and in a few years the waiting list had disappeared, the number of beds in the geriatrics service reduced and the rehabilitation resources concentrated.

A central concept of geriatric service management was to relate the use of resources to a defined population and its pattern of need. From the known characteristics of disease in later life it was easy to predict that the key feature of a successful geriatrics service would be ready access of older people to acute hospital beds, not, as had been assumed, to long-stay beds. A survey relating the resources used by successful services to their target populations supported this concept (Grimley Evans, 1981). In the context of Newcastle upon Tyne, and many other places, the readiest way to achieve this was by what came to be known as the integrated model combining acute general medical and specialist geriatric services (Grimley Evans, 1983). Local data had shown that putting a consultant physician with special responsibility for the elderly (PSRE) on a general medical ward team increased the number of older people admitted but actually reduced bed occupancy through disproportionately reducing their length of stay. And this was done not by transferring them to geriatrics beds but by getting them back home again. This setting also seemed more effective than others in recruiting students to geriatrics (Parkhouse and Campbell, 1983). As a service model it pre-empts the creation of those Departments of Second-rate Medicine for the Elderly, so beloved of NHS accountants.

Newcastle students were lively and stimulatingly sceptical, but coming straight from A-level chemistry they were more attuned to DNA and cell membranes than to the less material aspects of medicine. In one of its series of curriculum revisions, the medical school introduced a two-year multi-disciplinary Human Development Behaviour and Ageing Course to which I contributed a series of lectures. As so often with "introductory" courses, many students only saw the point of it after they had done the rest of their five years. Many were initially unsympathetic to teaching in social sciences, but enlightened clinicians could be moderately successful in demonstrating the

relevance of some concepts from social science to the practical world of medicine.

After a couple of years as an NHS consultant I was appointed to a new Chair of Medicine (Geriatrics). With a research grant from the Department of Health, Professor Sir Martin Roth, Dr Klaus Bergman and I set up a joint geriatric and psychogeriatric research group. This was small – too small by modern standards – but enabled us to explore some aspects of the epidemiology of later life. One of the features of medical practice among older patients is that one is dealing with problems rather than simple diagnoses. Epidemiology is one useful approach to structuring problems in ways that have implications for both clinical and public health medicine. Falls, fractures and dizziness provide examples. Fractures are not just a matter of osteoporosis; their epidemiology reflects the likelihood of falling at different ages, the things that cause falls (Prudham and Grimley Evans, 1981) and determine the nature of the fall, and a faller's protective responses in distributing the force of the fall between wrist and hip (Grimley Evans, 1996). If you break your hip your chances of survival are related to your mental state and how many nurses there are on the fracture ward (Grimley Evans *et al.*, 1980). In old age, falling itself may indicate that your days are numbered if you fall indoors but not if you are out and bustling about in the world's affairs (Grimley Evans, 1992). Dizziness is more than one condition. Rotatory dizziness, in which patients see the world spin round them as if they had just stepped off a children's roundabout is related to risk of stroke (Grimley Evans, 1990) and probably includes a contribution from vascular insufficiency. Non-rotatory dizziness, an unpleasant loss of confidence in awareness of one's body's position and posture, is a risk factor for falls and probably represents a breakdown in the integrative action of the nervous system; for some temporary reasons the information from the sense organs in the joints and muscles does not match that from the eyes and ears.

The early 1970s were hope-filled years in the NHS. The financial envelope, as it later became known, was tight but flexible and enthusiastic clinician managers working with supportive administrators could get things done. Geriatric medicine, a specialty invented by the NHS, also enjoyed a special relationship with the Department of Health. After the oil crisis of the mid-1970s the skies darkened as the long march of politicisation of the service began with one of those periodic reorganisations. The medical profession was fragmenting, and there was even talk of a Royal College of Geriatricians. Sir John Brotherston as President of the Faculty of Public Health Medicine felt it necessary to convene a meeting to ask why public health doctors were not more kindly regarded by their clinical colleagues. The answer, sadly, was that clinicians still prided themselves on serving primarily the best interests of their patients and recognised a duty to fight the administrators and bureaucrats of the NHS when necessary.

Public Health doctors were seen, however good their intentions, as having joined the enemy; they had become apparatchiks. The academic departments of public health preserved the honour of the specialty in the eyes of the wider profession, but the underlying moral dilemma remains, and now affects all doctors caught up in the management structure of the NHS, not Tsars but commissars.

Academics should move around, and in 1984 I was invited back to Oxford, to take up a Chair established from NHS funds through the good offices of Dame Rosemary Rue. A primary task was to help in instituting an integrated model of geriatrics and developing a teaching programme. Thanks to the goodwill of most colleagues and the withdrawal of some others, the integrated service was established. But Oxford had its problems, one of which was a grievously under-resourced acute hospital service. It had also failed to realise the potential for becoming a University Hospital, managed by the University, dedicated to research, development, and teaching where all staff have University contracts. One once dreamed of a University Department of Geratology pursuing both animal and human research alongside the academic department of Primary Care. British medicine will continue to under-perform in the world scene until our major medical centres can allocate their work rationally away from the seductions of private practice and from NHS managers obsessed with meeting politically imposed targets.

Geratological research proved a somewhat lonely furrow to plough. On the principle of following need, I became increasingly concerned with dementia in a threefold approach of a community epidemiological study (Clarke *et al.*, 2004), a Cochrane Group[1], and a memory clinic. As other geriatricians had found, local activities rarely have any impact on national developments. On the wider scene, the most promising means of influencing events seemed to be through involvement in central activities. I was launched into an absorbing decade of committees in the Royal College of Physicians, the Department of Health, and the Medical Research Council. One of the most satisfying aspects was to see the MRC Health Service Research Panel evolve into a fully-fledged Board with its Chairman on the Council. It was an immense privilege to work with the nation's most distinguished professional colleagues and with civil servants of the highest intellectual and administrative calibre. It was also a revelation of how important it is for doctors to learn something of committee skills and especially of chairmanship. Committees should not be approached as fields of combat between conflicting and irreconcilable interests, or as bodies to be manipulated to pre-determined ends, but rather as groups of individuals engaged in mutually educational discussion seeking the common good.

In some specific initiatives, such as pressing for a combined prevalence and incidence study of dementia modelled on the Göteborg work (Berg, 1980), I had personal involvement through presenting the Department of Health with a

research design. Much time was then spent in running to and fro between a Department of Health that for operational reasons wanted the study done and the MRC that did not want to pay for it. The eventual compromise distorted the proposed methodology but at least the thing happened. There have subsequently been various attempts to deal with the central problem of balancing research funding appropriately between scientific exploration and service needs, none entirely successful. It is disastrous for a significant proportion of medical research funding to come under the control of politicians and their Departmental civil servants, but that of course is exactly what politicians and their civil servants desire.

Although I was able to encourage some good things to happen that might otherwise not have done, my main hopes in the endless trips to London were strategic. In addition to supporting Health Services Research in its broad sense, I wanted to urge wider recognition of the significance of the ageing of the population for clinical services and public health systems. I was determined not to be a conventionally clamorous advocate for older people against other needy groups in the population, but tried to ensure that older people were remembered as part of the national community with a legitimate claim on a reasonable share of its resources. It was not always a comfortable role, especially when caught in the crossfire between different government agencies, and conflicting advocacy groups. Most difficult to deal with, practically and emotionally, were the occasional politically motivated attempts to prevent Health Services Research that might produce results the government would not want to be known.

Work with the Committee on Medical Aspects of Food and Nutrition Policy (COMA) was of particular interest as it lay on the intersection between science and policy-making. Scientific issues form only one of the dimensions to policy making. The committee was largely insulated by its secretariat from any direct impact of lobbying by vested interests in the food and drinks industry, but there are also other wider and more legitimate considerations that ministers need to take into account in forming policy. Not least are costs and relative priorities in calling on the national budget. During my chairmanship of COMA it was necessary to emphasise again and again that the committee's task was to carry out science-based appraisal of options; it had no business to make policy recommendations. This was not popular with enthusiasts who saw recommendations from scientists as a way of putting pressure on ministers. It did, however, protect the committee from subsequent blame from politicians if "recommended" policy turned out to be unpopular or ill-advised. Ministers have the power, they must also bear the responsibility.

Government has subsequently met the general challenge of scientific influence on policy making by largely replacing scientific advisory committees by external reference groups (ERGs). The input of members of ERGs to policy is

marginal; policies are now determined virtually entirely by administrative civil servants and politicians. It would be unduly cynical to regard the role of ERGs as simply to give scientific verisimilitude to an otherwise bald and unconvincing narrative. But a scientist on an ERG must recognise that he or she is a player in a political game, not a scientific one. There can be little doubt that the central policy preoccupation of the National Service Framework for Older People, for example, was to exclude older citizens from expensive medical care in acute hospitals not, as would be hoped by a geriatrician on its ERG, to improve their well-being (Grimley Evans and Tallis, 2001).

The growth in HSR exposed challenging methodological issues. Appreciation of the contribution of qualitative methods is necessarily shaded by irritation at their over-frequent and futile use, especially in nursing research (Grimley Evans, 1997a). Quantitative methods tell us 'what', qualitative can help with answering the 'why' of human behaviour – essential to the predictive power that is the ultimate justification for empirical science. Rather than accepting a low response rate in a clinical trial why not ask refusers what they did not like about the idea? There were also ethical dimensions to research design. Pervasive was the polarity between collectivist and individualist views of the function of the NHS (Grimley Evans, 1997b). Is it an instrument of government control to ensure a population healthy enough to serve the purposes of the State? Or is it a service responsible for helping individuals achieve their personal life goals? Unfortunately, the public health perspective and some more limited conceptions of evidence-based medicine can be deployed as rationale for collectivism. There is an Orwellian disjunction between the present government's claimed commitment to patient-centred medicine and its enthusiasm for guidelines and imposed protocols. Quality Adjusted Life Years (QALYs) continually rear their ugly Hydra heads. As a means of helping individuals decide between different treatment options QALYS can illuminate choices, especially if deployed in association with an individual quality of life estimation such as provided by SEIQOL (Mountain *et al.*, 2004). But as a means of deciding which diseases and which patients are worth treating, QALYs are an offence against the equal respect for all individuals that J.S. Mill (1859) set out so succinctly as the bedrock of British liberty. Equity has to be a central concept in a socially responsive system of medicine. Equity requires equal treatment for equal need, and need has to be treated as proportional to capacity to benefit, but what is to constitute benefit should be decided by the receiver not the purveyor of care. It is the individual patient's concept of utility that should determine his or her treatment, rather than the health economist's idea of social utility.

Older people, with limited life expectancy and, all too often, disabilities, are inevitably discriminated against by collectivist thinking. Since the creation of their speciality in 1948 geriatricians have felt a duty of general advocacy for

older people both in the NHS and in society as a whole. We must fear that traditional geriatric medicine will now be a casualty of the new managerialism in the NHS. Older people are likely to be increasingly subjected to osmosis into those parts of the health and care systems that statistics do not reach. Yet one could argue that ageing remains the single most important challenge to the stability of civilisation. There are far too many people in the world; in the long term we have to adapt to a new demography with a smaller population, a lower birth rate and longer life expectancy. But with the biological inevitability of age-associated disability it becomes economically crucial that the length of productive life is sufficient to underwrite the costs of pensioning any subsequent period of disability. The social and economic stresses that will arise if this balance is not made will be destabilising and fundamentally de-civilising. There are two ways to approach this challenge. One is to identify and avoid the causes of age-associated disability in environment and lifestyle; this is the business of the medical epidemiologist. The second way is to uncover and manipulate the biochemical processes that underlie the genesis of time-dependent disability. Some of these processes may become, somewhat arbitrarily, defined as "diseases" and swept up into a portfolio of medical research. Subtler effects, and particularly the universal processes of intrinsic ageing, need to be pursued as a biological rather than a restrictively medical issue. There are promising signs that biological geratology, almost extinguished in the UK in the 1960s by the withdrawal of MRC funding from scientists such as Alex Comfort and A. T. Welford, is now again emerging from the shadows (Kirkwood, 2001). In the absence of a National Institute on Ageing in the American model, the problem will lie in persuading scientific funding agencies to protect long-term strategic research against noisier populist pressures. More than ever ageing research needs powerful activists. Given their numbers in the electorate, the most powerful could be older people themselves.

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Notes

1 The Cochrane Dementia and Cognitive Improvement Group (www.jr2.ox.ac.uk/cdcig)

6

Ploughing a furrow in ethics

Raanan Gillon

My path to becoming a hybrid of general medical practitioner and philosophical medical ethicist doubtless began before I was born. My father, a descendant of Amram the father of Moses and a host of rabbis, rebelled against his rabbinical training in Mea Sharim, the most orthodox Jewish part of Jerusalem, and came to England to study law in the 1930s. Here, at University College London, he met my mother, daughter of a family scattered with Church of England clerics, including a Dean of Christ Church, Oxford. She converted to Judaism, somewhat cynically and essentially to please my father and his extremely orthodox mother, before they married, went to Jerusalem and had three children of whom I was the eldest. After a few years my father decided he preferred England (my mother was quite happy in Jerusalem, especially because of its climate) and so the family moved to London in 1948, when I was seven.[1] I went to the excellent Marlborough primary school in Chelsea, did well in the eleven plus exam and got a London County Council scholarship to the Anglican 'Royal, Religious and Ancient Foundation' of Christ's Hospital – the bluecoat school – no doubt helped by the fact that several of my mother's family had been schooled there. I was helped too by my parents income as freelance writers, which was small enough to pass under the school's maximum parental income barrier, for Christ's Hospital was then rigorously maintaining its 16th century objective of providing education only for the children of the poor.

I was one of two or three Jewish boys out of 1,100 pupils, and we were told that we had to go either to chapel or to synagogue. Since I had ceased – cocky little brat that I was – to believe in the existence of a god, I chose the easier option of school chapel (the nearest synagogue was in Horsham several miles away), and despite my atheistic Jewishness enjoyed the daily church ritual (twice a day on Sundays) and especially the singing. I still feel more at home in a church than a synagogue, a bit odd for a Jew. However, the school chaplain's efforts to persuade me to become confirmed in the Church of England were no more successful than my father's to persuade me to prepare for or have a Jewish bar mitzvah. Nonetheless, I greatly enjoyed the argument and the reading, learned something of both religions, and unlike many atheists was and remain sympathetic to both religions and indeed to religions in general, especially for their ethical concerns and their fostering of a sense of responsibility to others, particularly to those who are less able to look after themselves.

At medical school I began to develop a specific interest in medical ethics when a consultant obstetrician/gynaecologist brusquely refused to authorise an abortion for a 14 year old school girl, on the grounds that 'the slut will just get pregnant again if I give her an abortion', or words to that effect (this was well before the 1967 Abortion Act). He was scornfully impervious to discussion when I attempted to argue on her behalf. What puzzled (and enraged) me was that he was not conscientiously opposed to abortion in principle on the grounds,

for example, that it was morally equivalent to murder – a stance that I could have respected even though I thoroughly disagreed with it. But he was well known to do abortions when he thought they were 'appropriate – otherwise …'

otherwise abortions were 'illegal and against medical ethics'. My next foray into medical ethics was also at medical school, when I entered for the British Medical Association's student essay prize, the title for which had been set as 'Suicide and voluntary euthanasia'. Much to my surprise I won it despite arguing in favour of a change to the Suicide Act to permit voluntary euthanasia (I have long since rejected this view, essentially because of worries that the resulting change of social ethos will put pressure on frailer and sicker members of society to 'volunteer' – at worst even to 'be volunteered' – for euthanasia, despite their real preference to stay alive). I think that prize cost me a paediatrics house job: after the title of my prize essay was elicited at the job interview there were no further questions and I was turned down; instead I was offered a post for which I had not applied – on the geriatrics firm!

When I qualified in 1964 I asked the Regius Professor of Medicine, Sir George Pickering, at Oxford (where I was doing my clinical training), if I could do a doctorate in medical ethics. Definitely not, I was told, in no uncertain terms, during a half hour dressing down in his office. In the first place, medical ethics was not a subject one could *study* – one acquired it in the course of learning to become a good doctor. If by chance medical ethics *were* amenable to study it could only usefully be studied by mature doctors with a wealth of clinical experience upon which they could draw. And if by some utterly remote chance a young doctor could usefully study medical ethics that young doctor certainly shouldn't be me.[2] Still pursuing a PhD in medical ethics I tried the philosophy department, but they said they couldn't possibly 'poach' a student from another faculty – especially not so powerful a faculty as medicine. Other universities were no more ready to accommodate my peculiar desire to study medical ethics.

Having been turned down for medical ethics study and for the paediatrics house job I had wanted, and having myself turned down the geriatrics house job I had been offered, I decided to look for house jobs in the Bahamas or Hawaii – new experiences, better climate. In the long drawn out process of arranging this I earned some pocket money as a freelance medical journalist, and was soon tempted into becoming a well paid full-time professional medical journalist in the newly developing 'freebie' medical press, rapidly becoming deputy editor then editor of a weekly medical newspaper called Medical Tribune. In this exalted role I had discussions with health ministers and chief medical officers, editorialised about anything that caught my fancy, including David Steel's Abortion Act (my paper was the only medical publication to support his Bill), medical politics, and The Future of Medicine. I even started to dabble in local politics, reaching the dizzy heights of Chairman of my local Labour Party ward,

before deciding that there was too much of an obligation to stick to the party line for me to enjoy – or succeed at – being a politician.

After seven years as a medical journalist I was sacked. The paper was losing money, a sufficient cause for such a sacking in journalism. In addition I had become increasingly protective of my staff's jobs and rights – to the extent that I was elected 'Father of the Chapel' (leader) of our small branch of the National Union of Journalists. This admittedly unusual role for an editor was not at all appreciated by the American millionaire owner of the paper, Dr Arthur Sackler (he of Sackler Gallery fame), and certainly did not help me retain my job.

Before deciding which career to pursue next I was determined to do those house jobs. A few months of desperately swotting unemployment later I found myself, not in Hawaii or the Bahamas, but, as the result of several strange coincidences, at University College Hospital in London as house surgeon to the Professor of Surgery. After several house jobs, junior and senior, a locum registrar post, and eventual success in 'the Membership' exam (Membership of the Royal College of Physicians), I fell into the role of part-time general practitioner in a student health service, and again started to look into the academic study of medical ethics. Perhaps I could study moral philosophy with a view to pursuing this objective, I suggested to David Hamlyn, Professor of Philosophy at London University's Birkbeck College. Somewhat tersely, he told me: 'Philosophers, Dr Gillon, have to be trained, just as doctors have to be trained. I suggest you do our philosophy BA and see how you get on'. So I did, working part-time as a GP and part-time as a student of philosophy at Birkbeck's evening classes and on my two days off each week.

The argument about how much training or education in philosophical ethics is required by doctors interested in medical ethics continues to this day. My own view is that they only need enough to be able to reason critically about their moral obligations as doctors – they do not need to become 'philosophers' or do philosophy degrees. Nor do I think that philosophy is the only appropriate route for acquiring such skills in critical moral reasoning. However, for me at that time Professor Hamlyn's advice proved excellent. Not only did it result in my obtaining a good grounding across the range of academic philosophy, it also helped me develop a very different, fascinating and intellectually stimulating way of thinking about the world.

From early on in my studies I became increasingly aware of the moral conflict between respect for individual autonomy and various conceptions of justice – and of the extremely varied range of these conceptions of justice. And I became increasingly dissatisfied with views that I had somewhat inchoately adopted whereby social justice was to be achieved by the imposition by democratic governments of unspecified combinations of actions to maximise happiness 'for the greatest number', combined with actions that sought differentially to benefit the

poor and generally those in greatest need. It was not that I doubted that max-
imising welfare with differential concern for the poor and needy were important
objectives of social justice but rather that I increasingly realised that respect for
people's autonomy was another important objective, and that it could not – or
should not – simply be subordinated to welfare maximisation and the concerns
of the poor and needy whenever these clashed.

Respect for autonomy, I realised – or decided – was undervalued both in the
medical and the political spheres. Why should the democratic process make such
a big deal about respecting voters' autonomy once every few years at election
times – and in between assume that the views of 'the people' on specific issues
need neither be sought, nor, when obtained, necessarily accepted? I became
decreasingly willing simply to override people's autonomy either on grounds of
maximising welfare, or of differentially helping the poor and needy, or on
grounds that the elected governors' views of what was best should override the
views of the governed. Although I remained somewhere near the middle of the
welfare/liberty seesaw, I was moving across the fulcrum from the paternalistic
welfarist side to a Millian libertarian, autonomy-respecting side (Mill, 1859).
Among the effects of this shift was my resignation from the Labour Party which,
in the early 1970s, seemed to me to be creeping very much too far towards pater-
nalism. It was a difficult decision to take, for I had been brought up in a family
environment of vigorous democratic socialism – but having made it I felt a sense
of intellectual and personal liberation. It was great to feel free to make my own
political assessments without much sense of guilt if they opposed the local or
national party lines.

Nonetheless, Nozik's (1974) 'Anarchy State and Utopia' came as a great shock
– this was surely libertarianism gone mad, I couldn't help feeling – both when I
first read it, and still today. Yet its ruthless reasoning left me with two clear resid-
ual insights – there was no intellectual, political or moral obligation to accept
maximisation of any good – happiness, welfare, preference satisfaction or what-
ever – as *the* over-riding moral objective; and in any intellectually reputable
theory of social justice, respect for people's autonomy, while it need not be, as
Nozik seemed to argue it was, the only or the over-riding moral concern, was
nonetheless a crucial one. My even stronger impression was that both doctors
and politicians in power – of whatever party – tended to underrate individual
autonomy.

In 1979 I got my philosophy degree, registered for a PhD and toyed briefly
with giving up medicine altogether, so entranced was I by philosophy. On the
other hand I did want to do something *practical*, and my reason for studying
philosophy had been to understand medical ethics better and then in some way
promote such understanding within medicine, probably by teaching it. I was
also increasingly enjoying being a doctor, and whenever I compared the two

activities I always felt sure that while I was quite often of some use to my patients as a doctor, I doubted that I was of any use to anyone when I engaged in the highly enjoyable intellectual sporting opportunities offered by philosophy. So I continued my part time medical practice with a view to 'doing' medical ethics in some part-time capacity. After all, John Locke, whose work I was reading in connection with my proposed thesis on the concept of a person, had combined philosophy with medical practice, so why shouldn't I follow his example?[3]

In 1980 I successfully applied for the editorship of the Journal of Medical Ethics, which Alastair Campbell was vacating after inaugurating it in 1975. So I gave up my just-started PhD to make time for the JME editing-work, which I was to enjoy for the next twenty-one years, while continuing my part-time general practice. Of course, I couldn't have done that these days, when a PhD is an entrance qualification to any sort of substantive academic role, but those were early times in the development of medical ethics; the Pickering perspective (that one couldn't *study* medical ethics) was widely shared, especially among doctors, and we enthusiasts ploughed our own furrows as best we could. Though I slightly regret that my great work on 'medical ethics and the concept of a person' was never written, I ruefully have to acknowledge that others have, both before and since, written most of what I was going to write. It would also have been fun trying to put my PhD supervisor, Professor Roger Scruton, to rights about some of his political views.

Among the most influential medical ethics ploughmen was the Reverend Edward (Ted) Shotter, a Church of England cleric. Ted, in the 1960s, had started a series of medical ethics evening discussion groups for students in London medical schools, under the rubric of the London Medical Group, a model that was subsequently taken up by most British medical schools. As the medical students involved became doctors with a continuing interest in medical ethics, Ted founded first the Society for the Study of Medical Ethics and then the Institute of Medical Ethics (IME), along with both the Journal of Medical Ethics, and the Bulletin of Medical Ethics. Both publications still flourish, though the Bulletin has been run independently of the IME by Dr Richard Nicholson for many years. Other medical ethics enthusiasts who emerged from Ted's ecumenical 'stable' included the Reverend Brendan Callaghan SJ, psychologist and erstwhile principal of Heythrop College in London University, The Reverend Kenneth Boyd, Professor of Medical Ethics in Edinburgh University and General Secretary of the IME, The Reverend Alastair Campbell, the first editor of the Journal of Medical Ethics and Professor of Ethics in Medicine at Bristol University, and Dr Roger Higgs, Professor of General Practice in London University and the first Case Conference Editor of the Journal of Medical Ethics. It has been an enormous pleasure to work with and learn from these IME colleagues and friends over the years.

My own introduction to Ted Shotter, and thus to his associates, had come from Dr Gerald Stern, neurologist and guru to many, including me, at University College Hospital, and one of the many doctors interested in medical ethics whom Ted had drawn into the London Medical Group. When I first met the Reverend Ted (now the *Very* Reverend Ted) I said it was very nice of him to see me but I doubted if I, as a Jewish atheist, would be quite the sort of person he would find helpful. "On the contrary" he assured me, "If you don't mind my saying so I think you're a Godsend". And we've been working together in medical ethics for over 30 years, for even after he took up the post of Dean of Rochester Cathedral, Ted continued, and continues, his active involvement with the IME, of which I have been Chairman over the last few years.

One of the earliest – probably *the* earliest – of the formal courses in philosophical medical ethics in the UK was started by the Worshipful Society of Apothecaries, an ancient City of London Guild that until quite recently awarded licenses to practise medicine. It already ran a very successful diploma course in the history of medicine and in the late 1970s it decided to inaugurate a diploma in the philosophy and ethics of medicine. At Ted Shotter's suggestion I was asked to sit in and act as a sort of intermediary between the doctors who would be studying for the diploma and that strange demi-mortal, an Oxford University *philosopher*, who would be lecturing to them. My role as a medical doctor finishing a degree in philosophy would be to interpret and intercede between the two sets of beings, on those doubtless many occasions in which they would be unable to understand each other. However, the new lecturer, Dr Michael Lockwood, proved to be as lucid a communicator as he was brilliant a philosopher, and my presence as intermediary was entirely superfluous. On the other hand I learned a lot from Michael and enjoyed my Saturday morning classes as much as all the proper students did – as well as learning to do a certain amount of co-teaching myself in the light of Michael's expert example. Later, Michael taught at King's College London as an external lecturer on a new diploma course in medical law and ethics started up by the medical lawyer Professor – now Sir – Ian Kennedy.

Ian's prestigious Reith lectures on BBC radio, delivered under the doctor-provoking title of 'Unmasking Medicine' (Kennedy, 1981), had blown open to public scrutiny the whole arena of medical ethics. I had, in my first editorial for the Journal of Medical Ethics, welcomed Ian's central claim 'that the scope of medical ethics properly embraces society at large and must not be the concern solely of doctors', though I had criticised their 'combative style and phraseology' (Anonymous, 1981). In the mid 1980s, when Michael Lockwood's commitments at Oxford became too onerous to permit him to continue also lecturing at King's, Ian asked me to take over the medical ethics lecturing while he continued to teach the medical law half of the course. I did this for several years and

sat in on many of Ian's excellent medical law lectures, and learned to appreciate that, like medical ethics, medical law too was both intellectually stimulating and also full of disagreement, debate and uncertainty. The course was upgraded from a diploma to an MA in medical law and ethics, and it remains one of the most successful and sought after in a now very wide field of available postgraduate courses in medical ethics.

Another important early (and continuing) intellectual influence on my understanding of medical ethics was John Harris, whose first paper in medical ethics I had published in the Journal of Medical Ethics (Harris, 1981). Although we disagree about some important substantive issues, his ability to argue both straightforwardly yet extremely cleverly, as well as his marvellous inventiveness and wit, have been sources of – somewhat envious – admiration. He now adorns the Journal of Medical Ethics as its co-Editor-in-Chief.

Michael Lockwood had introduced me to a book that was profoundly to influence the development of my understanding and teaching of medical ethics. This was the first edition of 'Principles of Biomedical Ethics' by Tom Beauchamp and Jim Childress (Beauchamp and Childress, 1979). They made the startling claim that *all* serious moral thinkers could agree on four fundamental prima facie moral principles, regardless of their different moral, religious, philosophical, cultural and social backgrounds. Those principles were (in no order of priority) respect for autonomy, beneficence, non-maleficence and justice. Such a grandiose claim seemed frankly absurd – we all know don't we that there are *no* moral principles about which all serious moral thinkers can agree? Yet on reflection I certainly could find no reason to disagree with these four prima facie principles myself, and as I increasingly tried them out in my teaching and on my colleagues and friends I became more and more convinced that Beauchamp and Childress were right – these were potentially universally acceptable prima facie moral principles.

But while I increasingly accepted (and still accept) that these four principles provide a firm basis of universal basic moral commitments, and expect them eventually to be recognised as such within international ethical consciousness, they of course leave much work to be done. In particular they do not provide a solution to the crucial problem of what it is right to do when the principles conflict, as principles so often do. Nor do they address the issue of their proper scope of application (to what or to whom do these prima facie moral obligations apply?). And they also leave a great deal of work to be done, and agreement to be sought, as to what each principle actually means and substantively requires. What is it not to harm, to benefit, to respect autonomy, to be just or fair and what is required of us to fulfil these prima facie obligations? Each of these questions requires careful analysis, but – in my view at any rate – the prima facie obligations to respect autonomy and not to harm are relatively straightforward

to understand and translate into substantive prima facie requirements for action and withholding from action (mostly, though by no means entirely, withholding from action). Benefiting others, although apparently straightforward, is complicated both by the objective/subjective debate about benefit, and, more severely, by what I suspect is irresoluble disagreement about the proper scope of our obligation to benefit others – whom or what are we morally obliged to benefit, and to what extent? That our obligation of beneficence is necessarily limited is obvious, but where those limits should fall remains a matter of political, religious, cultural, social and ethical controversy, and in the end, so it seems to me, is a matter of negotiation and political and personal decision and commitment.

In 1983 I set up a one week intensive course in medical ethics at Imperial College, introducing several approaches to ethics, including the four principles approach, as well as consideration of several staple issues such as paternalism, truth telling, euthanasia and resource allocation. I was greatly helped in setting it up by the cooperation of James Barratt, a London nurse educator with the London Borough of Camden who was keen to involve nurses in such medical ethics continuing education. At first I ran the course with my Health Centre secretary (or perhaps it was the other way round) but after a few years the administration was taken over by Dr Mervyn Jones and his excellent team at the Imperial College Centre for Professional Development. It has been held each September since 1983, approved as continuing education for GPs Consultants and Nurses, and attracts an international range of applicants, as well as an excellent and varied range of speakers. However, back in 1983 I remember a somewhat alarming phone call from the then Registrar of the General Medical Council (GMC) indicating that he had been 'surprised' to be told that I had instituted a course for doctors and nurses in which 'nurses are encouraged to question the instructions of their medical colleagues. Can this be the case?' I assured him that reasoned argument was the basis of the course and that all course members were encouraged to apply reasoned argument to any issue whatsoever that was relevant to medical ethics. I never received the half anticipated 'warning letter', and these days, I'm pleased to relate, the GMC intermittently pays to send staff members to the course.

Increasingly interested in the question of how best to introduce medical ethics into British medical education, in 1984, with the help of a travelling fellowship from the Medicine Gilliland Foundation administered by the Royal College of Physicians and paid study leave from Imperial College, I went on a six week fact finding tour to find out how medical ethics was taught in the USA. This is not the place even to summarise the many valuable insights I picked up from the large number of medical ethics teachers I met there (Gillon, 1990), but my tour strengthened my view that critical medical ethics was vastly more developed in America than in the UK, or indeed anywhere else. On the other hand, quite a

lot of good work in medical ethics was then going on in the UK and Europe, of which the Americans were largely oblivious. These days there is far more international interchange in medical ethics, encouraged both by the growth of international academic bioethics journals (of which I am pleased to say the Journal of Medical Ethics remains one of the most important and highly cited) and also by the biennial conferences of the International Association of Bioethics.

While the Imperial College intensive medical ethics courses attracted a few doctors each year (we started with about a dozen and now get 50–70 course members annually), in the mid-1980s philosophical (or 'critical') medical ethics was given a far wider exposure to medical consciousness when the Editor of the British Medical Journal, Dr Stephen Lock, kindly took a gamble and accepted my proposal to write a series (eventually 26) of articles on the subject for the BMJ, later published as a book (Gillon, 1985). It was a time when medical ethics was very much in the public eye. Among the high profile medical ethics issues that in the mid-80s had followed Ian Kennedy's Reith lectures were the report of Mary (now Lady) Warnock's Committee on in vitro fertilisation (DHSS, 1984), the Sidaway case on informed consent[4], and the Gillick case on parental rights versus confidentiality[5]. My BMJ articles concerned the ethical arguments and issues stemming from another legal case, that of Dr Leonard Arthur, who had sedated and allowed to die a severely handicapped newborn infant with Down's Syndrome who had been rejected by his parents. The articles concerned a wide range of philosophical issues emerging from the case but relevant to medical ethics in general, including (of course) the Beauchamp and Childress four principles.

In 1987, with the help and encouragement of two consultants at St Mary's Hospital Medical School, John Matthews and David Mitchell (the former now a consultant haematologist in Canada the latter now Medical Director at St Mary's), I began to teach medical ethics to medical students at St Mary's, which a few years later merged with Imperial College. At one stage I found myself in the odd and somewhat overextended position of being employed both as part-time Director of Imperial College's staff and student health centre and a partner, later senior partner, in the associated National Health Service general medical practice, and also as a Visiting Professor at Imperial College's medical school as well as a Visiting Professor at King's College and editor of the JME. Those were hectic times.

In 1995 I was awarded a Personal Chair in medical ethics at Imperial College, my half day a week of paid ethics work was extended to two days a week (which, in combination with my three days a week pay as a GP, led to a full time salary for the first time since my days as a hospital junior doctor in the early 1970s). At my instigation I was allowed to try to establish a Centre for Ethics in Science,

Technology and Medicine at Imperial College, provided I could attract sufficient outside funding to pay for it. Alas I could not. My embryonic 'Analytic Ethics Unit' at Imperial was disbanded, and there remains a lacuna – at Imperial College specifically and in the UK in general – for teaching and academic posts in the ethics of science and technology.

The field of medical ethics education, however, slowly continued to expand. Perhaps its greatest breakthrough in medical education came in 1993 when the General Medical Council (1993) decreed, in its booklet, 'Tomorrow's Doctors', that medical ethics and law should be part of every medical student's core (required) curriculum. This was followed in 1998 by a consensus statement about the proposed contents of such a core curriculum in medical ethics and law by some 40 teachers of medical ethics, drafted on their behalf by Professor Len Doyal and myself. The consensus process took several years, starting with much discussion among medical ethics teachers in London at our regular meetings in what later became the medical ethics and law subject group of the University of London. These discussions were then extended to all, or almost all, of the medical ethics and law teachers in the country via quasi-Delphi process[6] e-mailing (though I have to admit that sometimes the processes were more Delphic than Delphi). Almost all the participants then met for a hard-working one-day conference at St Thomas's Hospital Medical School, after which there was penultimate redrafting, final Delphi process e-mailing and then, at last, consensus followed by publication in the Journal of Medical Ethics and on the BMJ website (Consensus Statement by Teachers of Medical Ethics and Law in UK Medical Schools, 1998). This core curriculum has served at least as an aspiration for the content of medical ethics and law teaching in UK medical schools, though a survey currently in preparation will probably reveal that few if any medical schools fulfil it in practice. Nonetheless, its objectives seem reasonable ones for all medical students to have studied before they become qualified as doctors.[7]

Reasonable, but also in some cases very difficult. Among the most difficult are the issues of justice. While every moral thinker is in favour of justice, even agreeing on what we mean by justice is difficult. In the context of my medical practice I was repeatedly struck by the moral tensions between respect for autonomy, benefit for one's own patients, differential concern for those in greatest need, the utilitarian objective of overall welfare maximisation and other competing conceptions of justice. For example, my medical partners and I were constantly trying to do our best for our own patients and argued vigorously for more resources from the local family practitioner committee (a precursor of the primary care organisations that now manage general practice). Yet by (successfully) asking for funds to provide, for example, psychotherapy and physiotherapy at our practice, had we *unfairly* deprived other practices whose patients were more

socially deprived than ours? Respect for patients' autonomy was also in potential conflict with their best medical interests and while I was keen to respect the autonomy of my patients I was also keen to do what was medically best for them, and not to perform medically useless, let alone medically dangerous, actions, even if they wanted me to do so. Justice was clearly the issue, but what theory of justice was I to use? I have to confess that I am not much closer to a substantive answer than I was in my original BMJ articles about this question (Gillon, 1985, chapters 14 and 15). But I am clearer about some of the necessary components of such a substantive theory.

Everyone can, I think, agree that the notion of equality is an essential component of any account of justice; yet, as Aristotle pointed out in the 'Nichomachean Ethics' some time ago justice is not, and cannot plausibly be defined simply as treating people equally, or as treating them as equals, or as giving people equal consideration, shares or opportunities. Even if one accepts the Aristotelian claim that justice is a matter of treating equals equally and unequals unequally in proportion to the relevant inequalities (sometimes known as Aristotle's formal theory of justice), that too does not get one very far substantively. What *are* the relevant inequalities (and indeed the relevant equalities)?

In the context of health there is widespread agreement that health care *need* is a relevant criterion – a relevant inequality – so that a substantive theory of distributive justice for health care will require its distribution in proportion to the health care needs of the population. But again, even if the contentious concept of need is elucidated and agreed, meetable need distinguished from unmeetable need, and then differentiated from mere meetable desire or want, still need cannot plausibly be the only moral criterion – the only relevant inequality – in a morally acceptable theory of distributive justice for health care. First, suppose people with considerable health care needs autonomously refuse the relevant health care, a plausible theory of health care justice must surely allow them to do so. Second, what if meeting a few people's very great health care needs prevents the remedying of a large number of other people's relatively small health care needs? A plausible theory of justice surely requires *some* interplay between meeting the very great needs of a few and the smaller needs of many. Third, what if distributing health care resources in proportion to health care need prevents maximising overall health care gain? A plausible theory of justice will surely have *some* place for the notion that when resources are limited as much benefit as possible should be obtained for each available unit of those limited resources. Fourth, if the providers – or potential providers – of the resources for meeting other people's health care needs autonomously refuse to do so, would a plausible theory of distributive justice for health care simply override such refusal? Or should such a theory have at least some place for respect for the autonomy of those potential providers, despite the resulting reduction in benefit to those in

need? Fifth, shouldn't a plausible theory of justice have some place for differential priority to be given to those in special relationships (for example, shouldn't such a theory accommodate some *fair or just* priority to be given by parents to their children, or doctors to their patients?). Sixth, a plausible theory of justice should surely have something to say about the relative moral importance of using scarce resources to provide for those in need, and using them to reduce or eliminate any existing resource allocation arrangements that are unjust/unfair?

Then comes the major complication of the scope of the prima facie obligation of justice – to whom (or even to what?) do we owe the obligations of justice? Here it has increasingly seemed clear to me that the scope of our obligations of justice must vary both according to the particular obligation, and according to the nature of the entity to whom or to which that obligation is owed. Thus we owe all other *people* (by which I simply mean all entities of full moral status) prima facie obligations of non-maleficence and respect for their autonomy. However, we surely do not owe *all* other people obligations of beneficence – not even prima facie. Yet by hypothesis we do owe *some* other people *some* obligation of beneficence. And it is in this area – the obligation of benefiting others, as distinct from the obligations not to harm them and to respect their autonomy – that the obligations of justice are most opaque and contentious. Unless one is prepared to be committed to the belief that using our national taxes differentially to benefit the health of our own nationals is morally *unjust* then one must be prepared to accept that the scope of distributive justice in health care is not universal and that it is indeed just or fair to favour, in the distribution of our own health care resources, largely derived from taxes democratically raised within our own nations, those who live within our own nations. If so, while it is morally admirable to extend health care benefits to others outside our own nations, it is not morally obligatory, but supererogatory; i.e. above and beyond the call of duty. Under such an account, it is indeed morally open to democratic decision how much to extend such benefits; but of course, the more generous to others such democratic decisions are, especially to those in need, the more they are morally admirable.

Conversely, if we reject this – to some shocking – claim, on the grounds that our *obligations* of distributive justice are prima facie universal and thus include all with health care needs (and why stop at health care needs?), then we are morally committed, at least prima facie, to a massive reorientation of our available resources towards those in need throughout the world: we are committed, again at least prima facie, to the early Christian and later Marxist moral dictum, to each according to his need, from each according to his ability (whether or not he and she and their democratic processes are willing to cough up). I am clear in my own mind that we do not owe even prima facie obligations to benefit all in need of health care, and my clarity about this stems from the general truth

that the scope of our obligations of beneficence (of any sort) are not even prima facie universal, unlike the scope of our obligations of non-maleficence and respect for autonomy. Whether or not I am right, an adequate theory of distributive justice for scarce health care resources will have to address this issue too.

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Notes

1 Until recently I had understood that we'd come to London in 1947, in case any eagle-eyed reader has noticed a discrepancy here with an earlier potted biography.

2 I had had a somewhat uneasy relationship with this professor ever since, at his party to welcome new clinical students, I had refused to drink his South African sherry and earnestly lectured him about the anti-apartheid movement and the importance of boycotting South African goods.

3 Admittedly Locke seems to have restricted his medical attentions largely to one patient, the Earl of Shaftesbury.

4 Sidaway vs Board of Governors of the Bethlem Royal and the Maudsley Hospital. 1985. AC 871.

5 Gillick vs West Norfolk and Wisbech Area Health Authority. 1983. 3WLR 859; 1985. 2 WLR 413; 1986. AC 112.

6 A long introduction to the Delphi method is at www.is.njit.edu/pubs/delphibook/ch2b.html

7 The twelve subject headings of the medical ethics and law core curriculum are: informed consent and refusal of treatment; the clinical relationship: truthfulness, trust and good communication; confidentiality and good clinical practice; medical research; human reproduction; the 'new genetics'; children; mental disorders and disabilities; life, death, dying and killing; vulnerabilities created by the duties of doctors and medical students; resource allocation; and rights.

7

The jungle: an explorer's experiences of health services research

Walter W. Holland

Introduction

I became an epidemiologist through chance. While doing my National Service as an RAF Medical Officer I was invited to run a controlled trial of a new adenovirus vaccine, intended to reduce the frequency of respiratory infections amongst young RAF personnel. I was selected because of four factors (three of which were present in my punch card record):

1. Before entering the RAF I had received more clinical experience than my contemporaries (my entry to the RAF had been deferred to enable me to complete a piece of research).
2. I had experience of research and an additional research degree.
3. Most importantly, I owned a car.
4. The more senior individual originally chosen to supervise this trial had developed tuberculosis.

The trial of the vaccine was never done: it failed its safety test. This trial was to be undertaken by the Epidemiological Research Laboratory of the Central Public Health Laboratory, Colindale. Thus, in January 1957 I was in limbo – but not for long. That month Professor Tommy Francis, from Ann Arbor, Michigan, on a visit to Hong Kong, noted that a new influenza virus had appeared there, which would probably arrive in the US and Europe later that year. I was offered the opportunity to develop a surveillance system for the RAF for this predicted outbreak and to assist in research on preventing it.

In the 1950s medical education did not include much (if any) epidemiology, but I decided that a major new influenza outbreak would be interesting to study. My interest in epidemiology thus was aroused and I acquired experience in the subject – over the next five years – at Colindale, at St. Thomas' Hospital, at the London School of Hygiene, and at the Johns Hopkins School of Hygiene in Baltimore. While at the latter, I was able to do a major epidemiological study on respiratory disease, visit most major US centres of epidemiological research, and take part in teaching. I introduced a course in epidemiology for medical students at the Medical School, unheard of in this haven of technology. I returned to the UK in October 1962, to a Senior Lectureship in Social Medicine in the Department of Medicine at St. Thomas' Hospital Medical School, with the intention of developing epidemiological research.

St. Thomas' Hospital had recently appointed a new chief executive, Bryan McSwiney, known as Clerk of the Governors. One of the problems he faced was the need to modernize the content and handling of medical records. Computers were on the horizon and he wondered if they could be applied. He sought advice from one of the Ministry of Health's Medical Officers, Dr. M. A. Heasman, who

had responsibility for information. Heasman advised McSwiney to wait for my return from Baltimore and then seek my help, as he knew that I had done research on medical records and had used a computer.

Initial hospital studies (1962–1969)

Shortly after my return, Bryan McSwiney approached me. With the available computing facilities and knowledge at that time, I did not think it would be feasible to computerise the entire medical record, but it might be possible to do so for the patient summary and the results of tests. The first step was to determine the availability and adequacy of these items of information in the medical record. I enlisted the help of another medical colleague, Edward de Bono (later of lateral thinking fame) (Holland and de Bono, 1964). Examination of the patients' records showed that in order to obtain a reasonable record of the course of illness, one would need to have a pro-forma, improve doctors' handwriting, and have access to the nurses' notes. We also demonstrated the difficulties of using optical scanning to translate the record into a form suitable for computer analysis, in spite of the promises of the computer firm, who had assured us of the feasibility. I learned of the need to involve nurses, technicians, pharmacists, porters and medical record librarians in order to obtain a complete account of the patients' experiences. Apart from the account published of this work, we wrote a confidential memorandum to the Ministry of Health from the hospital, to warn them about our unfortunate experiences with the computing firm. Imagine my surprise in later years to find that this firm had become the preferred contractor on several Ministry of Health contracts. A long time later, I met on a train the Under-Secretary who dealt with these contracts. I enquired why this preferential status had been given after the report we had submitted. He replied: "the letter was destroyed on receipt as it might have influenced future commercial policy". An important lesson for a researcher about how decisions are made.

As a result of this initial experience of working with the hospital, and the realisation that epidemiological methods and principles could be applied to the problems of the health service, I became involved in a series of studies. By then the Medical School had created a Department of Clinical Epidemiology and Social Medicine responsible for teaching, service and research, and comprising of a medical statistician, a medically qualified epidemiologist, a social scientist and several field workers, all of whom had nursing/health visitor qualifications.

St. Thomas' major problem was the need to rebuild, as German bombing during the war had destroyed half of it. The hospital's role had always been to provide services to the local community. Our Department thus became involved in a variety of studies in which we applied our research capabilities. It was

necessary for my discipline, and health services research (HSR) in general, to demonstrate to the institution in which we worked that our research was soundly based and useful to the institution. All our studies at that time depended on co-operation with other hospital staff. I was fortunate – I had been a medical student, house officer and registrar at St. Thomas'. I had done clinical research and was considered to be a respectable clinician. The institution had committed itself to provide me with a career and to foster what was then known as Social Medicine after I had completed my training as an MRC Senior Clinical Research Fellow. The commitment of St. Thomas' to what was then considered a fringe subject was not as unusual as some might think, even though St. Thomas' was considered the epitome of "conservative London medicine". This was a misapprehension – St. Thomas' had always been in the forefront of "population medicine" concerns. It prided itself on looking after the population of Lambeth. It was one of the first London Medical Schools to have an academic professorial department in medicine. Its alumni included Florence Nightingale, as well as John Simon, the first equivalent of the Chief Medical Officer. But of course, there were also many traditional consultants – some, who beneath their "Harley Street" exterior, harboured radical, progressive ideas.

The genesis of HSR in the UK (1965–1972)

Our studies used epidemiological and social science methods, and were some of the earliest examples of multidisciplinary HSR in the UK. The Department of Clinical Epidemiology and Social Medicine was, at first, viewed with a degree of suspicion by the Medical School and hospital. We were the only clinical Department with explicit population interests and responsibilities, and only trivial responsibilities for individual patient care – a strange animal in a London Medical School.

The 1960s were a time when the Ministry of Health began to be interested and concerned with HSR. This was probably due to the need to develop a hospital building programme to replace the ageing, decrepit stock that had survived World War II, and the recognition that medical practice was changing. At the beginning of this era the Ministry had an in-house Social Research Unit, which performed what would now be considered HSR. It was recognised that in-house research was unlikely to be very persuasive to the health service. The Chief Medical Officer (CMO) was Sir George Godber (Lock, 1993), probably the best CMO of the last century. Godber attracted a number of extremely able medical officers. Two of these were Dr. Dick Cohen, a very senior medical administrator from the Medical Research Council, who became Deputy Chief Medical Officer, and Dr. Max Wilson, a former medical officer in the Colonial Service, who became a Principal Senior Medical Officer. Both of these had a background

and interest in research. The Principal (lay civil servant) in the Ministry Division concerned with research was Mr. John Cornish, with a background in Operational Research in the Navy during World War II. Outside the Ministry was the Nuffield Provincial Hospitals Trust, directed by Gordon McLachlan, who had also served in the Navy during World War II. The Trust, from its foundation before the War, had always supported research in health services.

It was these five individuals who, in my opinion, served as the promoters and initiators of HSR in the UK. Cornish had in the early 1960s allocated £3,000 of the Ministry's budget to operational research. He interpreted this as research into health services, and it was this money that helped to seed HSR in St. Thomas' and some other units.

From our perspective it was important to establish that we were capable of attracting research funding for population-based research (rather than clinical research) from outside sources, in order to strengthen our credibility within our institution. St. Thomas' had a very large endowment fund that funded both clinical research and some patient services (e.g. a patient library). It was usual for staff to obtain research funding from this source, much easier than going to the MRC or another authority. We were fortunate to be early in the field and that the research we did was of general as well as local use. We were thus able to obtain outside funding. The Ministry rapidly recognised the utility of HSR – and led by Godber and Cohen, supported by Wilson and Cornish, developed a mechanism and strategy for HSR, well described in 'Portfolio for Health' (Portfolio for Health, 1971; 1973). By 1970 there were a number of units, programmes and projects involved in HSR. It is not my intention to provide an account of all the early HSR – I will restrict myself to recounting some of the events in which we were involved.

General practice developments (1966–1974)

Although more than half of all medical graduates in the UK became general practitioners, only Edinburgh had an academic unit of general practice before 1965. At St. Thomas' the Medical School had always seconded students to general practice, if they so wished. St. Thomas' prided itself that the majority of its graduates became GPs (in contrast to Johns Hopkins, at that time, 90% of whose medical students became academic specialists). The School had been persuaded by Stephen Taylor (later Lord Taylor), a former graduate, who had undertaken a study of the quality of British general practice in the 1950s (Taylor, 1950), that it needed an academic GP department. On my appointment I was charged with developing this department, in spite of the fact that my only experience of general practice was as a 3–week locum. I was told that my appointment in social medicine depended largely on my known expertise in

intra-arterial puncture and catheterisation, rather than my knowledge of social medicine! My first attempt to fulfil this commitment was to enlist the help of John Fry, a GP in Bromley who had done some pioneering studies on the work of a GP (Fry, 1973). I appreciated the need for a full-time academic, but where to find the money to pay for this? We had a local Lambeth general practice, which had been identified by Stephen Taylor as an exemplary model. The principal, though an excellent GP, was not an academic, and his practice could not support an additional partner from its NHS income.

George Godber helped us to find a solution. He considered that the appointment of a senior academic GP to the school was justified in order to develop HSR. He persuaded the Ministry to fund the post for up to 5 years. Because of his concerns about academic general practice he later persuaded the Secretary of State, Sir Keith Joseph, to approach large charitable foundations. The Wolfson Foundation endowed a Chair in General Practice at St. Thomas'.

Selected examples of HSR at St. Thomas' (1967–1979)

The Department of Health decided that it needed to establish a more stable milieu for HSR. It followed the lead of the MRC and initially established eight research units. At our unit in St. Thomas', we recruited young academics from a variety of fields – medicine, epidemiology, sociology, social psychology, statistics and economics, with the prospect of career progression in the new applied field of health services research. Problems abounded. There were few experienced researchers in any of the above disciplines eager to take the risk of pursuing a research career in such an applied field, in a medical school, rather than in their own discipline. To attract researchers of promise in London, we needed innovative solutions. It is too easy to forget how few trained researchers in the disciplines we needed were available in the 1960s. The majority of researchers recruited had little, if any, research experience. We therefore had to train them. To maintain and train them in their parent discipline, those in non-medical subjects were funded to spend up to two days a week in Bedford College for sociology, the London School of Economics for economics, and the London School of Hygiene for medical statistics. In addition, all research staff were expected to participate in undergraduate medical education and advise hospital (and later health service) committees.

One of the first pieces of HSR our unit undertook was focussed on new hospital building. Apart from Harvard Hospital (near Salisbury) built by the US forces, no new hospital had been built in England between 1939 and the mid 1960s, although many institutions had been repaired or refurbished. The design of new hospitals needed to reflect changes in medical practice. The "Best Buy" concept was to be tried in two sites, Frimley, on the borders of Surrey and

Hampshire, and Bury St. Edmunds in Suffolk. Patients would spend less time as inpatients and thus there was a greater need for outpatient and diagnostic facilities and the development of community care.

In 1968, our unit was invited by the Ministry to put forward proposals to evaluate these concepts at Frimley. After lengthy discussion within the Unit we met with senior members of the Department of Health. Following about two hours discussion the (very) senior administrative chairman of the meeting called a halt to the proceedings. He was concerned that the proposed research could demonstrate the inadequacy of the stated Departmental policy. The researchers, and the research members of the Department, tried to point out that the purpose of research was to demonstrate objective findings. However, he was unwilling to agree and wished for further discussion within the Department and with Ministers. As a result we were left in limbo for about six months. The Department eventually agreed that HSR, funded by them, could question and investigate Departmental policies.

Following this episode, we had no problems until the mid-1980s in the formulation or dissemination/publication of research that questioned Department of Health policies. In the mid-1980s, the Department tried to introduce measures that would inhibit critical research, but in our unit we were fortunate to be able to access funds from, for example, the Nuffield Provincial Hospitals Trust, which enabled us to avoid the consequences of these restrictions.

A second notable example of HSR, and one in which I have had a keen interest, focuses upon screening. In the late 1950s and early 1960s the concept of screening, or early diagnosis of disease, became popular. The Department of Health recognised that screening could be important for health improvements, but also had serious resource consequences. In 1968, we were asked to undertake an evaluation. If multiphasic (i.e. multi-system) screening was to be effective in the UK health system, it needed to be linked to general practice (South East London Screening Study Group, 1977). This was a new concept to many – screening was considered to be a public health activity undertaken in a public health centre. We undertook a randomised controlled trial in two large South-East London group practices, and although multiphasic screening could reveal a large number of conditions unknown to the doctor or patient, there was no reduction in mortality, morbidity, disability or improvement in function. Thus the extra costs of introducing multiphasic screening throughout the NHS – which we calculated would increase NHS costs by about 10% – could not be justified.

HSR is an applied field of endeavour. Practitioners of HSR are usually concerned that their findings are used. It is relatively easy to see the application of studies at the local or practitioner level. It is more difficult for HSR findings to be used, or to illuminate, health policies at the central level. I will therefore now

try to describe some of the ways in which HSR came to be used in health policy deliberations.

Advising government policy (1968–1974)

In the 1960s, discussion on the reorganisation of the NHS became popular. The tripartite (hospital, general practice, public health) structure was considered to hamper progress in the development of medical care. In April 1968, Richard Crossman became Secretary of State of the new Department of Health and Social Security (DHSS). He soon convened an advisory group on the functions of a reorganised NHS, to which I was invited.

Although I had been a member of a number of Ministry working parties on subjects where I had done research, this was the first occasion that I became involved in major health policy deliberations. My contributions were general and informed by my health service/academic experience. I cannot recall making any specific contribution that resulted in action. Following the election of a Conservative Government in 1970, the policy of unifying the NHS was continued. A series of Working Parties was established on how a unified structure could be made to function, and I was a member of the "Working Party on Collaboration with Local Government". This was concerned with such matters as collaboration between health and social services, health and education and health and the environment. I was able to draw on my experience of working in these areas and was able to contribute to ensure that adequate, workable arrangements were continued for research to be done across administrative boundaries, and that the essential public health functions were continued. As one might expect the conclusions were not, I think, ideal: satisfying several "agendas" always results in compromise. One only discovers the inadequacies later, but, by then, as I have found over the past 30 years, one is in the midst of further reorganisation, with different consequent problems. These committees opened my eyes to the dynamics of working with civil servants and politicians. The intelligence of senior civil servants was impressive, but their ignorance of practice, and, often, their belief in out-dated but popular "facts", amazed me.

During Richard Crossman's period as Secretary of State the inequalities in the distribution of NHS resources also began to become evident. Until 1970, the allocation of resources to the regions was based on the level of funding at the inception of the NHS plus an approximately equal percentage increase each year each region. This allocation method led to increasing differences between the regions, and, as a response, the DHSS introduced the "Crossman formula", whereby about 50% of the allocations were based on the level of utilisation of hospital services. The remaining 50% was still based on "historical" allocations.

By the time of the next Labour Government (elected in 1974), the geographic

inequalities in funding had actually widened. Since utilisation is based on the availability of facilities, and the South had more and newer facilities designed to increase throughput, it therefore did better than the North. This was an unacceptable situation.

Professor Brian Abel-Smith of the London School of Economics was the Chairman of the Advisory Group to our research unit and advisor to the Secretary of State. He suggested that the unequal distribution of resources was a problem worthy of consideration. We proposed an experiment to the Department of Health, by suggesting that areas should be "grouped"; for example, areas with high infant and child mortality should receive additional resources to improve maternity and child health services, areas with high cardiovascular mortality rates should receive additional resources for cardiology services and so forth. We could then evaluate whether additional resources were associated with improvements in health, and whether either "earmarking" or "general" resource allocation led to better results. These proposals were discussed and approved by the then Chief Scientist (Sir Douglas Black) and a meeting was arranged with David Owen (the then Minister for Health). The Minister declined to agree because he felt that the allocation of more resources to particular areas in this manner would be impossible politically. However, he stated that he was going to create a Resource Allocation Working Party (RAWP) to develop a solution, and invited me to become a member.

Sir Douglas Black was a delightful person to work with. He was an eminent clinician, but he was very concerned with public health issues. Although his relations with doctors was excellent, he did not enjoy dealing with politicians or civil servants, who found his questioning attitude difficult and, unlike me, did not appreciate his pawky sense of humour. I had known David Owen from his days as a neurology/psychiatry registrar at St. Thomas', and had shared laboratory space with him. We were not friends at St. Thomas', where people objected to his arrogance, although I respected his political commitment.

The first meeting of RAWP was an all-day meeting introduced and led by Owen. The Chairman of the Working Group, John Smith, thinking that he would please his Minister, arranged the luncheon seating so that David Owen and I sat at our own small table with him. David and I did not reveal to John Smith that neither of us enjoyed this experience. That said, David Owen proved to be an effective communicator regarding RAWP. My dealings with Barbara Castle were more distant. She was obsessed with the problems of private practice, and would not listen to my arguments that this was a relatively trivial problem. As a result of her policy of separating private and NHS practice, I observed a change in the behaviour of my colleagues, whose commitment to the NHS began to wane. Before her, my part-time NHS consultant colleagues, in spite of large private practices, were meticulous in fulfilling their NHS

commitments, and always gave priority to NHS patients if there was any conflict in demand for attention. Post-Castle, similarly situated doctors have been markedly less meticulous in fulfilling their NHS duties, and this has been a continuing source of concern to NHS managers.

Membership of RAWP was an interesting experience (Department of Health and Social Security, 1976). Other members represented administration, finance, nursing, medical administration, as well as civil servants representing different divisions of the DHSS. The first deliberations were concerned with trying to understand the reasons for the maldistribution of resources and what possible corrective steps could be taken. Solutions had to be linked to the budgetary cycle. We were convened in April 1974 to influence the 1975–6 allocation of funds. In view of the short time-scale, we agreed to put forward an interim formula, and then have a further period to consider a comprehensive formula for 1976–77.

The aim was that resources should be related to need rather than utilisation. For the interim formula, RAWP members were willing to accept that the size and age-sex composition of the population was a suitable measure of need. Studies were undertaken by my research unit to discover possible refinements to the formula (Palmer *et al.*, 1979; West *et al.*, 1980). The ultimate formula adopted was based on population size, age-sex composition, and standardized cause-specific mortality, with the main opposition coming from some DHSS finance officers, who had been responsible for resource allocation since 1948.

My advisory commitments during the 1970s also entailed policies relating to smoking. In the early 1970s tobacco manufacturers, encouraged by government, were interested in developing products that might be less harmful than normal cigarette tobacco. ICI and Dupont developed different cellulose materials which, when appropriately flavoured, were considered to mimic tobacco. The DHSS formed a committee under Lord Robert Hunter, Vice-Chancellor of Birmingham University, to ensure that these new smoking materials and additives were not harmful. The committee comprised a number of disciplines – clinical, pharmacological, toxicological, biochemical. I represented epidemiology. The new materials and additives passed the various laboratory and animal exposure tests and were ready for marketing.

The committee had accepted that it was essential that evaluation in humans should be done in such a way that one could draw valid conclusions; i.e. by randomised controlled trial. Before this could be done, however, it was necessary that the new products were acceptable to consumers. Factories were built to produce the "less harmful cigarettes". The experiment failed: few smoked the new products. Partly this was the manufacturers' fault, as they did not have the cigarettes in the shops when the consumers came to buy them. Partly, the failure was due to very effective anti-smoking propaganda by the Health Education

Council, who produced a cartoon that stated that smoking the new cigarettes was like asking people to jump from the 38th floor of a building rather than the 42nd.

As a result of this failure the DHSS and the manufacturers adopted a different strategy. They aimed to reduce the tar content of cigarettes, because tar was considered to be the main carcinogen. Testing the effectiveness of this strategy was going to be difficult and entailed an experiment in which people bought (and smoked) a harmful product. It was decided that this could not be done by the DHSS, since they could be attacked for promoting smoking. Thus, an Independent Scientific Committee on Smoking (ISCS) was set up with the same membership as above but with more epidemiologists. They reported and were accountable to the DHSS, but received substantial funding from the tobacco manufacturers. The ISCS then considered and funded a series of studies to assess whether low tar cigarettes really were less harmful than medium tar cigarettes. The results basically showed that low tar, low nicotine cigarettes were as harmful as medium tar cigarettes, because smokers of low tar cigarettes modified the way they smoked so that they continued to get their usual fix of tar and nicotine (Withey et al., 1992a; b). Nonetheless, a gradual reduction of the tar content of cigarettes was unlikely to do harm, and was thus continued as a government strategy.

Serving health authorities (1974–1988)

The NHS reorganisation of 1974 was of profound significance to the English Teaching Hospitals, as well of course to the organisation of heath services. Having played a role in devising the appropriate managerial mechanisms for an integrated health service, I was interested in the implementation of the new structure. I had already been involved, as a representative of the Hospital and the School, in some of the local discussions and negotiations, particularly on the details of management and district boundaries.

Professor Rhodes finished his term of office as Dean and was succeeded by Dr Derek Wylie, a senior anaesthetist. I was elected Sub-Dean. Derek Wylie was not interested in hospital/health service management but the new arrangements enjoined us to have a seven-man team – administrator, nurse, finance officer, representative of the hospital consultants, representative of the general practitioners, district community physician, and a representative of the Medical School. I represented the School. This group was labelled the District Management Team (DMT) and met weekly. The DMT was responsible for all aspects of the management of health services in the hospital and in the community, but my contributions were very general. Obviously they were illuminated by my research/academic experience and were, I hope, therefore rather more

soundly based than those of my colleagues, but by the rules of the day, all DMT decisions had to be by consensus. Thus the likelihood of a scientifically-based decision being implemented depended as much on advocacy/communication skills as on science, particularly as some of the members of the team were not trained in the interpretation of research findings.

In 1982, the DMTs throughout the whole country became district health authorities (DHAs), which each comprised of about 16 members. The local authority, local trade unions, consultant medical staff, local GPs, nursing staff, members of the local community and academics represented. I was nominated by the Medical School to be one of the academic members of our local DHA. In 1983 I became the elected Vice-Chairman of the Authority until I resigned in 1988.

During this time I continued to be involved in planning and finance issues, and the period was one of great turmoil (Kember and McPherson, 1994). Lambeth was a local authority with a Labour Party majority opposed to many of the policies of the central Conservative Government. The DHA members nominated by the local authority reflected those views. Thus, the meetings of the DHA were turbulent, amplified by the decision by the Secretary of State to appoint a new Chairman, the father of Virginia Bottomley, herself a future Secretary of State for Health. This period was when controversial policies, such as the contracting out of domestic and catering services, were first introduced.

My contributions to the DHA were obviously coloured by my experience of HSR, but the major concerns were more with the political conflicts between the DHA and the DHSS, the conflicts between members of the DHA with different allegiances, the difficulties of protecting the services essential for medical research and education, and the difficulties of an institution that was the single largest employer in a very deprived area at a time of great unemployment. This meant that when considering priorities for cutting back services, in addition to the clinical needs of the community, the members of staff who would become unemployed had to enter consideration. Perhaps the area of most concern was the provision of mental health services. West Lambeth DHA, in addition to the provision of acute psychiatric services at St. Thomas' Hospital and the South Western Hospital, had become responsible for a very large old psychiatric hospital, the Tooting Bec Hospital. Government policy was to close these large institutions and provide mental health care in the community and in smaller units. The Tooting Bec Hospital was also the subject of critical reports on the quality of the care it provided.

I will not enlarge on these issues here, other than to comment that DHA discussions were rarely concerned with rational, planned policies for these patients, due mainly to the shortage of funds, the desire to close the Tooting Bec and take advantage of the proceeds of development of the site, and difficulties with staff,

many of whom had worked for several decades at the hospital and were very resistant to change. In addition, there were difficulties in reconciling the different philosophies of psychiatric care, some of which were blatantly anti-doctor, and others of which were based on outmoded authoritarian principles. My contribution to these debates was limited, and, since I was a doctor who could not possibly have expertise in mental health, viewed with great suspicion by many of the lay DHA members.

My membership of health authorities illustrates the difficulties of identifying the contributions that HSR makes to the decisions and policies at the operational level. It is impossible to conclude that membership made a great difference, or was responsible for the initiation of any one policy. Membership of an authority by an academic with some experience of HSR probably improved the level of debate. I was influential in persuading members of the authorities, on some occasions, to consider policies and make decisions based on evidence rather than only on beliefs or political opinions. But equally it is salutary to appreciate that my opinions/statements were often neglected or ignored. The contributions of HSR to policies are most affected by the education/knowledge of the participants, and the individual researcher/academic influence is largely dependent on communication abilities. It is probable that advocacy is often more credible from an academic than from a non-academic. But one must remember that the majority of the concerns of health authorities have not been tackled by HSR.

House of Lords select committee on science and technology (1987–1989)

In the late 1980s concern about the funding of medical research began to surface. As a result, the House of Lords convened a committee to examine the funding of medical research and how priorities would be set for this (House of Lords Select Committee on Science and Technology, 1998). Sir John Butterfield and I were appointed as specialist advisers. The Committee consisted of 14 members, most of whom were of great eminence. The Committee was chaired by Lord Nelson, the Chairman of General Electric Company (GEC). The Committee sent a letter inviting the submission of evidence from both individuals and medical institutions. In the invitation, special emphasis was placed on evidence of how priorities are set, and over 200 responses were received. The Committee visited two London Medical Schools, the Royal College of Physicians of Edinburgh, Trent Regional Health Authority, Sheffield University, and the Imperial Cancer Research Fund Laboratories in Lincoln's Inn Field. Four members of the Committee, the Clerk to the Committee and I visited a number of prestigious American institutions.

The Committee was very concerned about the state of medical research, and HSR in particular. Not surprisingly, in view of its criticisms, the Government

did not accept the Committee's recommendations. It was particularly averse to the creation of an independent body, a National Health Research Authority (NHRA), but did accept that there were problems with the current mechanisms and level of funding. To meet the particular criticism of the lack of concern with "public health and operational research", a Directorate of Research and Development was to be created in the Department of Health, with a Director who, after some argument with the Committee, was to be given Permanent Secretary status and appointed a member of the senior policy group within the DHSS and the NHS. This, at least, raised the profile of HSR, and it was hoped would increase the output of research.

The first Director of this body was Professor Michael Peckham. His vision of HSR (which is what I will continue to call it) was rather different to that of most HSR researchers. His background was clinical, in oncology. Regional Directors of research and development were appointed in each of the NHS regions, but in only one of the fourteen regions (South Western) was an active HSR researcher appointed to the post. The rest were clinicians. These, of course, were usually concerned with and sympathetic to HSR, but their main concerns, like Professor Peckham's, were clinical. Thus, as one would expect, the majority of the emphasis in the next few years in funding HSR was on clinical projects, and relatively little weight was given to strengthening HSR.

A complex bureaucracy was established for decisions on HSR, including what HSR priorities should be. A lot of effort went into developing systematic evaluations of published research, including the establishment of the Cochrane Centre at Oxford. Although much of this was necessary, the major recommendations of the House of Lords Committee to strengthen the role and capacity of HSR were neglected. The program of research that was initiated by Professor Peckham is well described in his Rock Carling Lecture (Peckham, 1999). Peckham was succeeded by Professor John Swales, Professor of Medicine at Leicester University. During his term in the office, some of the House of Lords Committee's recommendations were implemented. There was more emphasis on HSR rather than clinical research, and new research on illuminating the effects of central policies was initiated in place of the emphasis on reviews of published research. In contrast to Professor Peckham, who was very acceptable to Ministers and most (though not all) of the permanent staff at the DHSS, Professor Swales was more critical of ministerial policies, and thus had a more difficult time. His term of office coincided with a great deal of turmoil within the DHSS, so he was unable to implement many of the policies that he may have wished to initiate. He was succeeded by Professor Sir John Pattison, a pathologist, who had been Dean of University College Hospital Medical School, and had been involved in the enquiry on BSE. It is not possible for me to comment on his role as I am now too far away from active research.

Faculty of Pubic Health Medicine (1989–1992)

Between 1989 and 1992 I was President of the Faculty of Public Health Medicine. The Faculty was a constituent member of what was known as the "Conference of Presidents of the Royal Colleges and their Faculties". There were 16 members of this senior body of the medical profession, which was not concerned with pay or conditions of employment, but with the standards and quality of medical practice. As such, it was regularly consulted by Ministers, Departmental officials and other bodies such as the Audit Commission and the GMC. We met every month for a full day of discussion, as well as on other occasions for meetings with other bodies. I was Vice-Chairman of "Conference".

This period was marked by great change in the NHS, and relations between the Government and the medical profession were fraught. The Government was intent on changing the structure of the NHS into a market with providers and purchasers. The Presidents were unanimously opposed to these changes. We feared that introducing a market into a system with no spare capacity would not work and that the deprived and disabled would be the group most disadvantaged by the proposed changes. We considered that the major problem of the NHS was the lack of resources, but the only area in which we were able to effect a change was in the conditions to be established to ensure that clinical standards were maintained. This was to be the task of a "Clinical Standards Advisory Group", an independent body nominated by the professions, charged with reviewing standards and quality of care on a regular basis. We were able to insert in the terms of reference that standards of care included ensuring equity of access; i.e. that access was to be still determined by need rather than demand.

Changes in the structure of the NHS meant that public heath practitioners (PHPs) were again reorganised – and had to take on new responsibilities. Almost all PHPs were sited in purchaser authorities; i.e. they became, once again, part of the managerial structure and separate from their medical colleagues in general practice or hospitals. The major task of the purchasers was to agree contracts with providers for the services their population needed. These contracts were complicated, and were legally binding. The PHPs were usually the only individuals in the purchaser authority with a medical qualification. This presented an opportunity for public heath. Resources could be used to promote the public health and to provide services in relation to need rather than to pay for services that providers considered appropriate. For example, in the contract for patients with lung disease the purchaser would be able to specify the provision of anti-smoking measures rather than only clinical treatment and diagnostic facilities. I had hoped some of the lessons of public health and health service research might be applied.

Unfortunately, although valiant efforts were made in some authorities, the PHPs were largely deflected from public health concerns and into management. Partly this was because of the Government's wish not to increase turbulence in the system, and their issuing of instructions that contracts between providers and purchasers should ensure that past patterns of service were continued and that major changes for providers should be avoided. The authorities were also very dependent on the medical expertise of PHPs in drawing up contracts, and some PHP's were enticed to become managers responsible for the allocation of large sums of money. They felt that this would enable them to have more power in influencing the pattern of clinical care, rather than to be involved in the much less prestigious and nebulous planning of public health services.

Conclusion

This brief history of my experiences and applications of HSR is but one "story" of how HSR was developed and applied during the period 1962–1992. I have tried to describe some of my involvement with those responsible for the implementation of health services policy. There are, I think, several lessons that can be learnt from these experiences:

1. HSR is a multidisciplinary field. Working in such a field requires time, patience, training and respect for all of the disciplines involved.
2. Since the purpose of HSR is to improve the provision of health services, close collaboration with those responsible for the operational delivery of services – doctors, nurses, therapists, managers and other staff – is crucial.
3. The findings of HSR must be implemented – this means that they must be disseminated beyond merely journal publications. I found that the best way was to work closely with an operational manager (Owen and Holland, 1976).
4. The major obstacle to the implementation of HSR findings is the outdated, rigid attitude of individual health service practitioners, and the personal prejudices, beliefs and experiences of politicians and their advisers. Means must be developed to circumvent these obstacles.
5. The dependence of HSR on political whims, tendencies and prejudices should be used constructively by researchers; for example, with respect to work on inequalities in health.
6. HSR can rarely answer directly health service policy questions at local or national level within the normal political timeframe of two to four years, but it can and should be used to develop appropriate knowledge, which can be applied when required. This means that policy makers should be encouraged to develop wide networks of advisers who are knowledgeable of research findings, rather than relying on the opinions of a select few. Further, all

changes in policy or practice should be evaluated rigorously, so that lessons can be learnt of what works and what does not.

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8

Confessions of a Graduate Nurse

Alison Kitson

Introduction

I graduated from the University of Ulster with a degree in nursing studies the year Margaret Thatcher became Prime Minister (not that either world views or experiences connected in any more intimate ways again). I was in the first cohort of an experimental nursing degree programme that had gone to the University of Ulster (then called the New University of Ulster). We were an odd bunch, a set of mouthy students whose opinions were sought by university and hospital authorities alike. Our four year integrated course was an experiment in collaboration and one from which, now looking back on it, I realised I learnt a lot, not necessarily in terms of formal knowledge, but in terms of understanding the politics of change and how you get things done.

Of course, one also discovered how not to get things done. Most embarrassingly, I can still remember my righteous indignation, as a first year student nurse, leading a delegation of student colleagues to complain to the Matron at Altnagelvin Hospital in Londonderry about standards of care in the ward where we were working. That anyone bothered to take any notice of us and, more surprisingly, that we found ourselves in the oak-panelled boardroom talking to the Matron, was a lesson from which I learned two fundamentally important things: one, only open your mouth to comment when you are furnished with appropriate facts; and two, look out for those people in the system who will use your ideological innocence or naivety for their own purposes.

Whether this incident helped to fuel the myths surrounding "graduate nurses" that accompanied us after graduation, I don't know, but I do remember thinking that under no circumstance would I follow the expected stereotypes; i.e. graduate nurses were too academic to be of any practical use and the best place for them was away from patients (i.e. either teaching or doing research).

My first staff nurse post was at the Ulster Hospital, Dundonald, just outside Belfast. I remember my first day on duty. It was a Monday morning in a general medical ward and as I walked through the brown swing doors to the ward I was approached by the Nursing Officer to tell me that, due to sickness, the senior staff nurse from my ward was being moved to take charge of another unit so I would be in charge. I could feel my throat tighten and knees weaken and considered the possibility that this would not be like any other morning: my reputation as a nurse was truly on the line. I survived more by luck than judgement, but again I learnt another important lesson – in order to survive in health care you need to build strong alliances and that if you are perceived as an intruder, 'an outsider', then the team dynamics will be severely affected.

This was the time when we worked 'split shifts' – short and long days. It went as read that the most junior staff nurse took on the bulk of the weekend work.

The sheer physicality of nursing is something to which you become acclimatised – like any job you get used to the pace and routine, but I can still remember those first few months coming to terms with the overwhelming tiredness and the responsibility of being in charge.

What struck me during this time was how direct and tangible my impact could be on the welfare and experience of my patients. I could make their experience bearable or move it to the more intolerable end of the continuum, not out of any malevolence or pre-meditation on my part, but out of lack of sensitivity, experience, perception, organisational acumen or knowledge.

Each day as I rushed up and down the ward I used to think of the things we had time to do for our patients, and then consider all the other things we could (and sometimes ought to) have done. I kept wondering who was in control? I began to find myself challenging the system again. Why did we have to do it like this? Why couldn't we do it differently? How do we know this is the most effective way to do it?

In desperation I wrote to my former departmental head, Ollie McGilloway, to ask him what I should be thinking about doing in terms of planning my career. His reply shot back and with it was an application form. It was for a Department of Health Nursing Research Studentship, the first of its kind being offered in Northern Ireland. I then spent an agonising few weeks wondering whether I wanted to conform to the graduate nurse stereotype; i.e. not a proper nurse but someone doing research. But the questions kept coming and the desire to change the system grew and grew. I ended up realising that if I didn't respond to these voices, I would be lost to nursing – my need to understand how to nurse was not just in the daily practice of it, but was also around trying to understand some of its most fundamental principles.

Doreen McCullough was the Chief Nursing Officer at that time and she, along with Ollie McGilloway, interviewed me. I had no idea about research or even how you went about developing a research question. I said I wanted to look at the quality of services for older people in hospital in Northern Ireland, and that's where my research career started.

Therapeutic nursing interventions: 1980–1984

Fred Kerlinger's (1973) "Foundations of Behavioural Research" became my bible; I read every geriatric text book I could lay my hands on, and raided the sociological, social policy, organisational and philosophical literature. I was particularly intrigued in how the concept of care was interpreted by nursing and by health care organisations more generally. This was epitomised by the growing debates in the early 1980s on the negative impact of health systems, in relation to, for example, Goffman's (1963) "Asylums", Miller and Gwynne's (1972) work

on systems of care for older people, and the impact of one or two serious scandals; for example, the Ely Hospital incident (Department of Health and Social Security, 1969).

Linked with this was the growing debate within nursing research circles, particularly in the North American literature, as to how nursing care was best conceptualised and enacted. It is hard to believe that in the early 1980s nursing care plans, based on the obvious logic of assess, diagnose, act and evaluate, were highly contentious issues. Column inches were being used up in the popular nursing press arguing about the merits and demerits of undertaking a systematic nursing assessment of patients' needs using activities of daily living (ADL) as a framework.[1]

The alternative to a systematic approach to organising care was the 'book system'; i.e. you had the ward bath book, bowel book, dressing book, mouth book and so on, and, depending on your grade and experience, you were assigned a task for the shift. The job of the ward sister was to make sure all the bits fitted together at the end of each shift.

In the early 1980s nursing was at the cusp of moving from a scientific management, Fordist approach to a more integrated, team based, problem-solving approach. The latter approach can be found in the management theories of Deming and Juran, and enabled teams of workers to take more control of their environment. Of course we didn't know it at the time, and so the ideological infighting without the evidential base to back up any convincing arguments for change continued unabated.

My contribution at this time was to test the hypothesis of whether ward sisters who were more aware of their therapeutic effect on geriatric patients improved the overall quality and experience of care than ward sisters who did not operate from a therapeutic base. Between 1981–1982 I surveyed all the staff working in elderly care in Northern Ireland, and from these data went on to study the way that nursing care was organised in wards where the Sisters scored highly on aspects of therapeutic care versus ward sisters who demonstrated a more traditional, routine approach. Serendipity always plays a part in research and my lucky break was that I located a "high" and "low" scoring ward sister in the same specialist geriatric unit. This meant that I could control the other extraneous variables that dog these sorts of evaluative studies.

What I found was that the vision, leadership and quality of the ward sister had a measurable impact on the quality of care and independence (as measured in terms of activities of daily living) of patients. I also observed that the therapeutic leader was able to "raise the game" of all staff in the ward. Without her explicit statement of standards of care, quality of patient care invariably reduced to the lowest common denominator. And depending on the prevailing (covert) culture, this lowest common denominator could manifest itself as

"warehousing" patients and "doing as little as possible", or over-protection and creating even more dependency (Kitson, 1984).

My thesis was timely in that by its completion there was a growing number of nurse academics and researchers who were looking at these issues. Pioneers such as Sue Pembrey and Alan Pearson in Oxford had set up a nurse-led community hospital in the sleepy Cotswold village of Burford. Steve Wright had begun to transform nursing services for older people in Newcastle-under-Lyme, and innovators like Bob Tiffany at the Royal Marsden were radically changing the way cancer nursing services were being organised and delivered.

The paradigm shift – for that is what it was – was beginning, and through Thatcher's reforms and the introduction of general management, nursing had to move itself out of the shadows of medical protection and into the harsh light of effectiveness, efficiency and quality assurance.

Standards and quality: 1985–1989

By 1985 I had obtained my PhD from the University of Ulster, had been lecturing on the undergraduate nursing degree programme for two years, and was writing papers from my PhD, speaking at conferences, and planning my next piece of research. It was during this period that I met two people from the Royal College of Nursing (RCN), David Rye, Director of the Professional Nursing Department, and Tom Keighley the RCN's Research Advisor. They told me of the work the College had been doing on Standards of Care led by the President, Dame Sheila Quinn. They were looking for someone to become the RCN's Adviser on Standards of Care and asked if I was interested in applying for the post. After much consideration I decided to apply and to my amazement was offered the post. Like many jobs I have since taken it was a blank sheet – I was asked to set something up. At that time Trevor Clay was General Secretary and he was putting the RCN on the political radar screen in terms of his challenges of the Tory health policies. Moving from an academic culture that admittedly had its own politics, to a professional trade union with a very high national and international profile, was a major shock to my system. I had to learn (very quickly) a whole set of new political influencing and leadership skills that would enable to me to begin setting up the Standards of Care Project for the RCN.

During the mid-late 1980s, the health care sector was fixated on measurement; Charles Shaw, Tessa Brooks and colleagues at the King's Fund were exploring medical and organisational audit, respectively; and the first wave of patient satisfaction survey debates was sweeping the country. Many Chief Nursing Officer posts in District Health Authorities and at local level had been given responsibility for quality assurance. This was variously understood as ranging from responsibility for the "non-clinical" aspects of the organisation to a

government initiated policy that had no real relevance or impact on the delivery of health care. Significantly, many of these nurse leaders began to look for ways to measure the impact of nursing services. A burgeoning industry developed in the use of imported nursing audit tools. Many of these measurement tools had their theoretical base in a more Fordist view of nursing; i.e. that tasks could be standardised and timed, and their outputs evaluated. They looked at generic requirements rather than discrete clinical need.

An alternative approach, based on Donabedian's seminal work on quality, was imported to the RCN via the Manitoba Nurses' Association and West Berkshire Health Authority. In 1979 the RCN set up a working group, chaired by Dame Sheila Quinn, to develop a set of national standards for nursing care. What seemed at first sight a straightforward task turned out to be more challenging. A Canadian consultant (from Manitoba) working for WHO was called in to help. She brought with her a set of documents outlining how standards could be written using a framework based on structure (what you need), process (what you do) and outcome (what you want to happen): in effect, the Donabedian framework. June Clark was a member of the working group (June went on to become President of the RCN in the early 1990s), and was working as a health visitor in West Berkshire. June took the documentation back to work with her and a colleague, Helen Kendall, working as a clinical practice development nurse, began to use the methodology to develop local standards.

In my role as newly appointed RCN Adviser on Standards of Care, the first thing I did was to look for best practice around the country and try to understand how nursing quality was being defined and measured. It was at this time I came across Helen's work. It was stunning in its simplicity – it combined a methodology for describing and measuring practice with a way of achieving local ownership and involvement. Working with Helen and other colleagues across the UK was an incredible period. The method – which came to be known as the Dynamic Standard Setting System or DySSSy – literally swept the country. Not only did it sweep through nursing and, to a lesser extent, to allied health professions and support services, but it also spread across Scandinavia and Europe during the late 1980s through my involvement with WHO.

Interestingly, a similar initiative had begun in general practice under the leadership of Donald Irvine and Ian Russell in Newcastle. At this time, the RCN's effort and the Newcastle work in general practice were probably the only real attempts to look at how quality improvement can be introduced from "the bottom-up". Before establishing our own evaluation research project to test the impact of the Dynamic Standard Setting System on nursing care and patient outcomes (The OdySSSy Project in 1994), I spent many a long hour discussing the pros and cons of "top down" and "bottom up" systems of quality assurance and standard setting.

Another privilege at this time was to be invited to run a workshop with Avedis Donabedian for doctoral students at Uppsala University – one of the oldest and most prestigious universities in Europe. This was in 1989 when I was three months pregnant with my first child. I can remember wondering whether I was suffering from sheer fright at having to perform in front of my intellectual heroes, or whether everyone felt like this three months into their pregnancy. From this experience, Avedis (and Dorothy, his wife, a public health nurse) and I were to become best friends, and he kept a close eye on my work, offering advice and guidance – and writing the odd poem for me as well.

By the late 1980s standards and quality had become recognised – if not universally accepted – terms within health care. The RCN had done a lot to educate nurses about the basic concepts, and there was a ground swell of optimism and expectation about how a clearer articulation of nursing interventions would lead to more precise measurement. Of course, there was still a view that nursing was part of a process, a set of instructions that did not substantially alter the course of the patient's journey to recovery or optimum health, and therefore did not require any special investigation.

Indeed, this view, albeit in a subconscious form, pervaded many of the research and health policy debates the RCN was involved in at that time. A case in point was the story of Burford Community Hospital, which will be described in the next section. The period 1985–1990 was like a roller-coaster. Not only did it coincide with a move from Northern Ireland to London, but a move from academe to the rough and tumble of a professional association with a high public and professional profile and the potential for significant influence. There was a lot going on in health care and in nursing. Old hierarchies were being dismantled and clinical nursing was moving into those spaces vacated by routine, traditional and defensive practice. It was at this point that my story moves to Oxford, and a period where the experience of shaping and influencing a national standards of care and quality improvement agenda was focused on innovation at the clinical practice research level.

The "Oxford experience": 1989–1995

In the early 1980s Sue Pembrey had been appointed to a new post at Oxfordshire District Health Authority to lead on clinical practice developments in nursing. Sue's vision was to refocus nursing's power base upon clinical practice, away from traditional management and education roles. During the 1980s she pulled a talented team of innovators and clinical leaders around her and began to change nursing practice. Alan Pearson set up the Nursing Development Unit in Burford Community Hospital, and then established a second one in the geriatric unit at the Radcliffe Infirmary in the Beeson ward.

The vision was simple; for nursing practice to transform it was necessary to invest in clinical practice units where nursing-led interventions could be tested and evaluated in a systematic, rigorous way. Such a change in clinical practice also required changes to the education infrastructure, and research investment and support. Sue had been working with key figures in the Oxford University Medical School and at Oxford Brookes University to cement the educational and research support. Ultimately, she wanted to establish an institute of nursing that bridged the divide between practice, education and research. She saw this being achieved through partnership between clinical medicine at Oxford University, the emerging School of Nursing at Oxford Brookes, and the District Health Authority. Supported by a start-up fund from the Sainsbury Trust, the Institute of Nursing was founded in 1989 in the Radcliffe Infirmary, and I was seconded from the RCN to help Sue set up the research programme. Our focus was practice research, and the first project I established was an evaluation of the Kiddlington team midwifery programme (Watson, 1989). Little did I know that I was about to walk into that oak-panelled room again and meet the equivalent of Matron.

Oxfordshire midwifery services had been undergoing quite significant transformation during the 1980s. The Perinatal Epidemiology Unity Unit, located in the Radcliffe Infirmary, had a new Director of Midwifery, Lesley Page, who had been appointed to transform the maternity services. Lesley had piloted team midwifery in Canada and wanted to replicate it in the UK and evaluate its impact. The idea again was relatively straightforward – in order to ensure continuity of care, pregnant women were assigned a "primary midwife" who was their main contact, and if they were not on call someone else in the same team known to the woman would be there to deliver the baby. The argument was that such personal care would improve maternal satisfaction, reduce the need for analgesia and medical intervention, and have no adverse impact on the baby.

In hindsight, it may not have been the wisest move to challenge the routine procedures of the obstetricians and gynaecologists of the John Radcliffe in such a direct way. It turned out to be something akin to David and Goliath, only this time the sling didn't work. Despite the best endeavours of the research team to produce a reputable piece of evaluative research which did show that mothers preferred the service and used statistically less analgesia, the level of resistance to any change was overwhelming. This resistance also affected many other innovations in the maternity unit, and what ensued was (in retrospect) a classic example of rejection of innovation because the key opinion leaders (in this case, the influential consultants and to a lesser extent the senior midwifery colleagues who felt overwhelmed by the ensuing confrontations) were not brought on board at an early stage.

What I also learned during this period was that no research is good enough

methodologically if the innovation being tested is ahead of its time or is too threatening. A similar experience lay in wait for the evaluation of the nurse-led units of Burford and Beeson wards. Patients were selected for the wards based on their need for nursing care (or therapeutic nursing interventions, including self-care management, rehabilitation, etc). The initial medical assessment was performed either in an acute ward or on the geriatric unit. Recruits to the trial were based on referrals where it was identified that the primary treatment for the patient was intensive nursing care. This intervention of course meant that the way nursing was perceived had to change to accommodate a more proactive, deliberate, planned approach to nursing care. At the beginning of the evaluation medical support was visible, but as the trial progressed things began to change. When referrals were diminished or stopped the patients on the trial dried up. The results were equivocal. Medical support was withdrawn, and the vision of Beeson and Burford began to wane (Pearson, 1988; Pearson *et al.*, 1992).

Yet paradoxically (and perversely as is the nature of the spread of innovation), the notion of nursing led units and team midwifery started to spread across the UK. Trials were set up at King's College Hospital, and a number of evaluations were undertaken of the nursing practice development unit initiative, sponsored by the Department of Health in England and led by Jane Salvage at the King's Fund. Despite these early setbacks in Oxford, a number of nursing-led initiatives in the Institute were started in dermatology, where Steve Ersser (1988), along with Terrance Ryan, the medical consultant, led an extremely successful programme. Also, Brendan McCormack became involved in community hospital services and demonstrated how some of the key therapeutic nursing interventions as developed at the Burford and Beeson wards could make a real difference to patients' experience of care.

This sort of work is like walking on wet sand. You put your foot down and can see a deep imprint, but then a wave comes up the beach and the imprint disappears. Does that mean that you never walked in that place? No, but it does say something about the timing and context of introducing change. Oxford in the early 1990s was a tremendously exciting place to be. Iain Chalmers was about to launch the Cochrane Collaboration, Muir Grey was involved in numerous initiatives, and Jonathan Asbridge had just become Director of Nursing at the John Radcliffe. Oxford Brookes went straight for a four year BSc degree in nursing, and used the well-developed Clinical Practice Development Team members, under the direction of Barbie Vaughan, to prepare clinical practice areas for students.

Another major project was the transformation of the medical unit wards from task to person-centred nursing. Alison Binnie was the primary change agent, supported by Angie Titchen, a research fellow in the Institute. This project was supported by a King's Fund grant and is an exemplar in terms of its real life

description of the complexity of organisational and cultural change. My job was to project manage and find the funding for the evaluation research projects during this time. I had been awarded a Junior Research Fellowship at Green College, Oxford, in 1989, and embarked on a series of seminars and meetings with innovators and academics in Oxford.

I also had responsibility for setting up a project to evaluate the impact of local standard setting on nursing actions and patient outcomes (the aforementioned OdySSSy Project, established in 1994). Working with a team that included Gill Harvey, Sophie Hyndman, and Paul Yerrell, we compared the impact of local standards for the management of post-operative pain on six standard-setting wards and six matched control surgical wards. The wards were scattered within a 100 mile radius of Oxford and I remember spending most of the early 1990s on some motorway or another. After three years work, our findings showed that whilst local standard setting did not have a significant impact on patient outcomes, the trend over time (a period of 12 months) showed that improvement to the way pain was being managed were demonstrable. This reinforced my own experience, which was that nurses do have an impact on the patient's experience and recovery, and that a challenge for us as a research community was to devise more sensitive ways of measuring such changes.

In a short period the Institute had grown from six people to around 25 researchers involved in a variety of externally funded projects. My primary objective was to forge formal links with other units, such as the Health Service Research Unit in the Public Health Department at Oxford, at that time led by Angela Coulter. We also developed very good collaborative links with Richard Pring and Donald McIntyre at the Department of Education in Oxford, and with Bill Fulford, a philosopher and psychiatrist at the Warnford. We were all embarked on a journey of trying to explain the complexity of professional practice, and we discovered that the challenges facing teachers, and psychiatrists, and nurses, were similar at the levels of theory, methodology, and practice.

It was a very productive time, albeit very challenging. In 1992, Sue decided to retire and I took over as Director of the Institute. I remember being interviewed for the job when I was seven months pregnant with my second child. Not something to recommend. The responsibility of being the Institute Head became one of securing research income streams for colleagues, and living from one research grant to another. Sue's vision of the Institute becoming an integrative structure that would meld the universities and the health authority together was not something that would happen in the early 1990s. Reorganisation of the Regional Health Authorities in 1994 meant that a whole tranche of research funding for the Institute, and many other research units in Oxford, disappeared. This was a time of crisis, and the demise and closure of the Institute would have happened if the RCN had not stepped in to support the research and

development work that had made the Institute one of the leading units of nursing practice developments in the UK.

Moving on: 1995–2002

What my experience in Oxford taught me was that if you want to change practice or health systems, you cannot afford to be isolated from mainstream policy and politics. The creativity, commitment and brilliance of colleagues I had worked with in Oxford could not contend with the power brokerage that was needed to be involved in and influence health policy. Again and again, I observed that it was not just the intellectual integrity of an idea that determined its uptake, but timing, context and political expediency. Whilst my understanding of health service research methodology had been enhanced during this time, I was still finding myself having to defend the right for nursing to evaluate and improve its own practice. This often struck me as bizarre. As nursing was one of the most labour intensive interventions in the health services, why was it not self-evidence that a proportional amount of investment was needed to be made in understanding what worked, why it worked and how we could change systems to accommodate the new knowledge. When I had these conversations with leading academics and policy makers, I was variously told that nursing research was not really health service research, or that the research policy agenda could not make exception for specific disciplinary groups.

The strategy I therefore adopted was one of integration: ensuring that our work on evidence-based nursing was integrated into the Certificate, Diploma and Masters Programme on Evidence-Based Health Care, developed by David Sackett and based in the Department of Continuing Education at Oxford University. I am indebted to colleagues such as Kate Seers, Liz West and Sophie Stanisweska, who have worked so tirelessly on this programme.

A second achievement during this time was to ensure that the work the RCN had done on Standards of Care was recognised by the Department of Health, and funded in a similar way to the audit and quality improvement work being undertaken in the other Royal Medical Colleges. This led to the creation of a first class information service for clinical audit and, subsequently, for clinical guidelines and clinical governance.

Thirdly, we were also able to establish a NICE Collaborating Centre for Nursing and Supportive Care based at the RCN Institute in Oxford (The Institute changed its name in 1995 from the National Institute of Nursing to the RCN Institute). Founded in 2000, the Collaborating Centre has led on the development of several clinical guidelines that have a direct impact on nursing practice. Such initiatives have been facilitated by: a) being able to demonstrate the quality and impact of the work; b) personal networks and involvement on

national committees where the nursing contribution to quality patient care can be articulated; c) anticipating policy trends and lining up the right teams to "ride the policy waves into the shore".

From 1995 onwards my role began to change again. My representation on a number of national groups meant that the nursing perspective could be presented at the appropriate time. Along with other nursing colleagues, we were involved in the Clinical Outcomes Group (COG), established by the then Chief Medical and Nursing Officers (Sir Kenneth Calman and Dame Yvonne Moores). This group helped to integrate clinical audit into the psyche of clinicians; it also led the way for the Clinical Standards Advisory Group (CSAG). I was fortunate enough to chair one of the projects undertaken by CSAG in the late 1990s – the review of epilepsy services across the UK – and was privileged to work with a first class research team led by Professor Simon Shorvon. CSAG paved the way for the work on the national service frameworks.

With the election of a Labour Government in 1997, the health policy landscape was set to change significantly. We watched the transmutation of several national groups into more focused programmes of work. Goodbye COG and CSAG; hello National Institute for Clinical Excellence (NICE), National Service Frameworks (NSFs) and Modernisation Agency (MA).

The rhetoric of New Labour was also starting to have an impact. More and more emphasis was being put upon a patient-led service, where systems worked on behalf of the patients and not the other way round. The RCN General Secretary, Christine Hancock, found herself increasingly involved in discussions with government officials on how best to transform services, and we were immensely lucky to be able to become involved in a number of very important national initiatives, such as the roll out of the RCN Clinical Leadership Programme led by Geraldine Cunningham in collaboration with the NHS Leadership Centre, and the introduction of consultant nurses (a role based on the seminal work of Kim Manley, one of the RCN Institute's lead practice development nurses).

As the quality improvement gurus of the 1980s and early 1990s were replaced by charismatic leaders such as Don Berwick from the Institute of Health Improvement, the health policy landscape began to settle down. Our primary objective was to ensure that we had the appropriate people involved in each national initiative – whether it was with the Clinical Governance team, the newly emerging Commission for Health Improvement (CHI), NICE, the multiple strands of work around the Modernisation Agency, the Cochrane Collaboration, or helping to influence the Research and Development policy agenda. It was reassuring that the agenda being promoted by New Labour was consistent with the vision that colleagues like Sue Pembrey, David Rye, Bob Tiffany and many others had battled to introduce. Almost overnight, it was

acceptable to talk about patient-centred care, and it was now de rigeur to celebrate the importance of supporting and investing in clinical teams and clinical practice. Complexity theory and complex adaptive system methodology were replacing straightforward reductionist cause and effect analysis. Nursing-led services were being actively encouraged in the wake of changes to medical working practice (such as the European Working Time Directive), and everywhere there was evidence of more integrated working.

As a then member of the Commissioning Group for the NHS Technology Assessment Research Programme, I was delighted to see the increasing number of studies that were evaluating the impact of nursing interventions on patient outcomes – studies that were properly constructed and supported by high class research teams. It seemed that nursing intervention research studies had come a long way from small-scale descriptive evaluations, to the major multi-centred trials that would provide credible evidence of impact.

Another trend that was emerging during the late 1990s was a fuller integration of nursing research activity into bigger interdisciplinary teams. Many of the most successful university nursing research departments were actively pursuing joint appointments and joint research programmes with other health service research colleagues. Initiatives such as the establishment of the Nursing Policy Research Unit at the London School of Hygiene and Tropical Medicine in the mid 1990s (funded by the Nuffield Trust) were exemplary in pursuing this interdisciplinary agenda in a way that put nursing research centre stage.

My main role at that time was as Director of the RCN Institute. I was responsible for overseeing a major organisational change in the Institute's postgraduate education provision, and had time only to pursue one area of research. This was around the understanding of how research can be introduced more effectively into everyday practice. Drawing on our experiences of a number of studies undertaken by the Institute in the early 1990s, myself and two colleagues, Brendan McCormack and Gill Harvey, constructed a conceptual framework proposing a formula that could predict whether or not an intervention was going to be successfully implemented. We argued that successful implementation of evidence (SI) was a function of three major elements (evidence (e); context (c) and facilitation (f)). We also argued that each element had three major sub-elements. We suggested that if you scored 'high' on each of the nine sub-elements, you were more likely to be successful in implementing the initiative. This work was published as Kitson *et al.* (1998), and became known as the PARIHS Framework (Promoting Action on Research Implementation in Health Services).

The team has expanded and we have been working since 1998 on refining and testing the validity and reliability of the PARIHS Framework, which has been used by several teams internationally, particularly by implementation teams

within the Veterans Administration System in North America and by Professor Carole Estabrooks and colleagues in the Centre for Research Utilisation at the University of Alberta. The UK team is now working on the development and testing of a diagnostic and evaluative tool that can be used by teams before they embark on a change management programme.

The here and now … and beyond

Twenty years on and I find that I am still asking the same questions of nursing and health care: who is in control? Why are we doing it like this? How do we know this is the most effective way of doing it? However, we now have a lot more evidence upon which to attempt to answer each of these questions. With the move of nursing education into higher education in the 1990s there has been more opportunity to invest in research. Despite having to make up a lot of ground, the numbers of high quality researchers in nursing is beginning to grow exponentially. Equally, with the sheer volume of health policy changes in the pipeline there has been a lot of opportunities for new nursing-led innovations to be introduced and tested for their benefits to patient care. The "black box" of everyday clinical practice – and particularly what happens within a clinical team context – is being put under the research microscope in ways that would not have been possible ten years ago.

Health service research methodology has also become more accepting of an eclectic approach. In addition to clinical trials looking at effectiveness, it is also important to fund detailed descriptions of practice, analyses of complex organisational change, multiple case studies, and a range of other studies that will help shed light upon the messiness of everyday clinical practice.

An ongoing intellectual challenge for me is to understand more clearly the difference between a "reflective practitioner" – i.e. a professional who regularly reflects upon and draws insights and conclusions from his/her everyday practice – and a practitioner who chooses to analyse clinical problems by withdrawing from clinical practice and becoming a full-time researcher. Are these people using similar analytic skills? Is there any benefit in keeping the reflective clinician in practice and supporting them in their problem solving? Does this create inferior evidence or knowledge because it has not been tested across multiple sites? Where do the everyday problem-solving skills of expert clinicians become indistinguishable from the deductive reasoning of clinical researchers? And how should we be positioning our practice-based disciplines so that they draw from and build upon these common skills? Rather than see research as something separate from improving clinical practice, I believe the next stage of development for health services research is to demonstrate improvements in practice through much greater collaboration and partnership between academics and clinicians.

This will require a shift in the way we conceptualise objective evidence, and will involve embracing multiple perspectives and complexity theory. Such realisations are influencing the wider academic community and it is necessary for the health community to embrace this next phase of development.

Within this wider theoretical context, there are a number of very practical things that also need to happen. First, we, as a research community, need to invest in more systematic research on the nature of the "clinical encounter". What actually happens between a practitioner (doctor, nurse, allied health professional) and a patient that leads to a positive experience? How do concepts such as trust, hope, dignity and respect influence the subsequent therapeutic outcome? Can such encounters be taught? How do we take our understanding of the clinical encounter and shift it into a wider understanding of promoting patient-centred systems of care? How do we promote more effective self-care and more effective self-management of long-term medical conditions?

So, the health service research agenda from a nursing perspective is still big and challenging. What needs to happen in very practical terms is continued investment in clinical academic careers for nurses and allied health professionals, as well as for medical practitioners, to enable the best and the brightest recruits to embrace practice development and research careers. There needs to be explicit fast-track programmes for candidates from every health care profession, to offer experience of working in centres of clinical practice and research excellence, so that they can see and feel and experience the excitement and joy of developing new initiatives, testing them and seeing patient care improve.

If all this happens then I expect that when I am 84 and negotiating with my carers, I will automatically be part of an evaluation programme or a clinical trial, and that my view as a patient will not just be to expect the best care that I can receive, but to offer something back to the community by relating my experiences of care and how I think it can be improved. And that's my goal as a nurse, as a researcher, as a leader and as a prospective user of the service. To contribute to the knowledge base of my profession.

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Notes

1 Roper *et al*. (1980) popularised ADL as a framework within nursing in the late 1970s and early 1980s.

9

*Confessions of an accidental policy analyst,
or why I am not a health service
researcher*

Rudolf Klein

It was entirely by accident that I first got involved with health services research at the beginning of the 1970s. After some twenty years as a journalist on the London Evening Standard and The Observer, I was trying to reinvent myself. My ability to react to events with enthusiasm and excitement – a required talent for good journalism – was diminishing; my prospects of promotion to editorial status were zero. Following the example of some other Observer journalists, maybe I could therefore transform myself into an academic. After all, I had spent much of my time on the paper commissioning, editing and, on occasion, re-writing articles from distinguished academics, an experience that had left me convinced that half the time I could do better or at least as well. And reincarnation as an academic would represent not only a return to family tradition – my father having been a distinguished medical researcher – but also to my first ambition on getting my history degree at Oxford: an ambition abandoned in favour of journalism only after failing to get a fellowship. Above all, I thought, an academic career would mean emancipation from the demands of editors and the constraints imposed by the competitive struggle for circulation, bringing with it the freedom to pursue one's own ideas.

It was, in many ways, an innocent, romantic fantasy, as I was to find out. Little did I know about life in universities, and the scope for pettiness and self-important complacency that it offered. Even less did I anticipate the way in which the status and relative pay of the academic profession would diminish over the next decades, while the pressures on it were to increase. So there I was at the beginning of the 1970s at a loose end, searching for a new career. When Bram Marcus, The Observer's medical correspondent, asked me whether I would be interested in helping a group at the London School of Hygiene to translate their research results into publishable prose, I leapt at the chance. Not because I had any specific interest in health care – I had none, despite my family background – but because it would give me a chance to move into this new world of intellectual exploration (as I rather naively saw it, only to discover subsequently that intellectual exploration was a luxury in the academic trade to be indulged in sparingly). In the outcome, I was to stay almost three years at the School of Hygiene. The initial part-time commitment eventually expanded into a full-time appointment as a Research Associate. My initial task of journalistic midwifery completed, I was able to develop some of my own interests.

These were highly educative years. They were educative in that I was working in the department of Professor Jerry Morris. An obsessional perfectionist, dedicated like his friend Richard Titmuss to bringing about a more just and equitable world, he was very much a crusader, but one whose chosen weapon was science. I read his Uses of Epidemiology (Morris, 1975) with some excitement, not that I ever shared his missionary zeal or was tempted to turn myself into an epidemiologist. But the sheer elegance and rigour of his exposition – the

demonstration of what could be learnt from population studies – captivated me. Also, his book taught me the importance of imagination and ingenuity in research. To demonstrate the importance of exercise in preventing ischaemic heart disease, Jerry compared the coronary death rates of bus drivers to bus conductors in London – the former being sedentary, while the latter were physically active, climbing stairs and so on. And, eureka, conductors turned out to have half the death rate of drivers. Further (yet another elegant touch), Jerry controlled for the effects of obesity by using the waistband measurements of the uniforms issued to drivers and conductors. Later, Jerry was, I think, disappointed in me: I was critical of the 1980 Inequalities in Health report (Black et al., 1980), of which he was one of the authors, and subsequently argued that health should not be used as a weapon for trying to achieve social policy goals (like a more egalitarian income distribution or better housing), which were desirable in their own right. However, in my time at the School of Hygiene, Jerry – although he could be intolerant of dissent – was generous in allowing me to develop my own interests.

My own interests reflected my experience as a generalist journalistic commentator, analysing policy issues and political conflicts. The health policy arena, I quickly discovered, offered plenty of examples of both. So, for me, the attractions of thinking and writing about health care sprang from the fact that there was nothing (or, at least, surprisingly little) special about it. Health care policies and conflicts could be analysed like any others. They involved struggles over power. They involved struggles over resources. They invited questions about institutional design. Initially, I suppose, this was an instinctive reaction rather than a conscious strategy. I only subsequently developed fully the notion of health care as a laboratory for analysing public policy issues. However, in the short-term, I found that the skills I had developed as a journalist could be used to write commentaries on NHS issues in the British Medical Journal and The Lancet, as well as the lamented and irreplaceable New Society: a fact that seemed to impress my colleagues at the School of Hygiene where, I discovered, even letters to the editor and obituary notes in medical journals appeared on the CVs of members of staff. Further, I discovered that for the time being I had a near monopoly of commentary on what might be called public policy issues in the NHS – like questions of accountability and organisational structure. It was, in a sense, all too easy and left me with the feeling (never entirely dispelled over the next three decades) that the main distinction between high grade journalism and academic analysis is that journalists take all the credit for the ideas in their articles, originality being a function of forgetfulness, while academics credit a reference even for their most original ideas.

All this came at the later stages of my stay at the School of Hygiene. For the first year or so I toiled on the project that had brought me there in the first place:

Professor Bob Logan's study of the dynamics of health care in the Liverpool region. And toil it was. The study, funded by the Department of Health and others, had started in 1963 at the University of Manchester (where Bob Logan was based until his move to the School of Hygiene). It had involved a revolving army of researchers who had long since spread themselves over the globe. It had produced a mass of unpublished working papers of varying quality and relevance. There were boxes and boxes of raw material. So this was not just a question of polishing up a draft into something publishable. In the event, it was research archaeology: trying to reconstruct the original design (if ever there was one) from the shards of evidence. For while Bob Logan was an engaging and stimulating talker, who introduced me to much of the health care literature, he was both disorganised and reluctant to put pen to paper.

For me chaos proved an educational blessing. If I had been required to do a straightforward editing job, I would have learnt little. As it was, I was forced to think through the whole project: the research questions, the methodology and the data. And it was an interesting, pioneering project: to examine the way in which Liverpool, the highest spending region in the country, used its resources. Did the high level of expenditure reflect a high level of need, or a poor use of resources? This was in the pre-RAWP days when resource allocations reflected history, not need-based formulae. To answer this question, a variety of studies had been carried out on the use of beds, the productivity of different surgical units, and thresholds for admission. And the evidence suggested that Liverpool's high admission rates – and long stays in hospitals – reflected not so much need as the availability of beds: what has since become known as supply induced demand.

Not only did the shards of evidence have to be put together; they had to be updated and reworked if the study was not to be seen as ancient history when eventually published (Logan et al., 1972). Here I had no competence whatsoever, and I relied on colleagues at the School of Hygiene. My main guide was Dr. John Ashley, a reluctant writer but a master of NHS data. To the extent that I have any grasp of NHS data, and any sense of how to handle statistics, it is due to his tuition and the long hours spent with him in arguing how to interpret the evidence. Between us, and with the help of David Robson, one of the members of the study team, we managed to produce a coherent, respectable monograph which immediately sank into a dignified obscurity. One lesson seemed clear. The timing of research is at least as important – perhaps more important – than its quality. If the Liverpool study had been published three years earlier – as it should have been, given a disciplined organisation of the project – it would surely have made much more impact.

There were other lessons I drew from my time at the School of Hygiene. First, never to engage in health services research in the conventional, narrow sense: i.e.

research designed to analyse/improve the performance of the NHS. Working on the Liverpool study had been stimulating, but it had not persuaded me to make the NHS (or the health of the population) my central interest in life. Moreover, I had been struck by the organisational incompetence of both the researchers and the funders (i.e. the Department of Health). Equally, I had been given an early clue to one of the problems of Department of Health-sponsored research: intellectual conservatism. When I proposed some work on the pattern of innovation diffusion in the NHS (a good idea, I still think), the idea was immediately turned down. Second, never to work – if I could possibly help it – in a medically dominated institution. In the 1970s the School of Hygiene was still a white-coat institution: statisticians might be respectable, but sociologists and even economists were distinctly marginal – a situation which had changed dramatically 30 years later when I returned to the School as a Visiting Professor. Doctors (as I occasionally pointed out when I wanted to annoy them) were the rats in my laboratory whose behaviour I was observing. They did not run it.

Before leaving the School of Hygiene to join the newly created Centre for the Study of Social Policy (see next section), I had completed my first book, Complaints Against Doctors (Klein, 1973). Having done some work on the role of the General Medical Council, I was lecturing about medical accountability when a student asked me whether I knew about the machinery for dealing with complaints against general practitioners. I had to admit to total ignorance. Deciding subsequently to remedy this, I found myself fascinated by the subject. My fascination may seem rather odd: why get excited by a somewhat arcane administrative institution – the local Executive Councils which administered the delivery of primary care and dealt with complaints – with a decidedly low public and political profile? In fact, the subject served as a tin-opener for a range of interesting issues, reaching way beyond the world of the NHS and the medical profession. It raised questions about institutional durability, or what later became known fashionably as path dependency: why had machinery invented by Lloyd George in 1912 survived so long? Equally, it raised questions about the nature of professionalism (and not just doctors) and about how professionals could and should be made accountable.

The last chapter of the book was entitled "Towards a Policy for the Professions", arguing the case for setting up a Council on the Professions. I would like to take credit for the resurrection of this idea 30 years later. Alas, my book was little noticed, little cited and (the ultimate humiliation) remaindered. For all that I count it as among the best work I have ever done, from which I drew a further lesson: that publishing too early may be as fatal as publishing too late. I suspect that if my study had appeared 10 years later, when professional accountability had become a major public concern, it would have attracted more attention.

A new incarnation

My spell at the School of Hygiene was the only time in my career when I worked in an intellectual environment exclusively concerned with health and health care. In 1973, I moved to the newly created Centre for Studies in Social Policy with a sense not only of gratitude to my former colleagues, but also of relief and excitement about the prospect ahead. The Centre had been set up, and was funded, by the Rowntree Memorial Trust. Its aim was to promote the analysis and discussion of the social dimension of public policy, across departmental and disciplinary boundaries. The Centre was generously staffed with secretaries and handsomely housed in a Georgian house in Doughty Street, conveniently central for maintaining contacts with politicians, civil servants and other policy makers. It allowed its staff to develop their ideas without any teaching duties or need to scavenge for research grants: a luxury which I was to appreciate fully only when I moved on to become a university professor in 1978.

I am not quite sure what persuaded the Rowntree Trustees to set up the Centre. But I do know that for me, at least, it offered an opportunity to practice the art of policy analysis. At the start of the 1970s, policy analysis was still a suspiciously regarded import from the United States. I remember a meeting at which a group of leading US exponents of the art met UK policy makers, ending with the civil servants among the latter sniffily concluding that policy analysis was what they had done all their lives. Its definition, even now, remains problematic and contentious. It can be seen as analysis intended to improve either the understanding of policy issues and processes (my own view), or to prescribe policy solutions. There is no agreed disciplinary base. The most brilliant exponent of the art, Aaron Wildavsky, was a political scientist; however, in US universities policy analysis has been largely appropriated by economists. It was precisely this lack of an established, defined disciplinary centre of gravity which, I suspect, attracted me: lacking a disciplinary base myself (except, in the distant past, as a historian), I could develop my own eclectic version of policy analysis. Indeed, the strength of policy analysis seemed to me then – as it does today – to lie precisely in the fact that it can and should draw on political science and theory, economics and sociology, as well as history.

Already in 1972, Hugh Heclo had written a review article on policy analysis in the British Journal of Political Science. Within a few years, British textbooks on the subject were to appear: on my bookshelves, the first seems to have been W. I. Jenkins's (1978) Policy Analysis. In the meantime, I embarked on a process of self-education. Anthony King, whom I had first met when I commissioned articles from him for The Observer, was my tutor in political science, which drew me into the rational choice literature. In particular, I was enormously impressed by the work of Mancur Olson on the logic of collective action and

Anthony Downs on democratic theory, as well as that of Braybrooke and Lindblom on decision-making. My intellectual horizons were further expanded by some of the American visitors to the Centre. Two in particular influenced me: Ted Marmor, who was to become a life-long friend, as a card-carrying political scientist taught me much, and Hal Wilensky, whose work on the evolution of different welfare states provided an exemplar of rigorous research methodology and the illuminations generated by a comparative approach. In effect, I became something of a do-it-yourself political scientist: a process of self-education which was to shape my work for the next three decades.

My first major enterprise at the Centre had nothing directly to do with health care, however. If the Centre had any direct US counterpart or inspiration, it was the Brookings Institute in Washington, and one of the best-known Brookings' products was their annual review of government spending. Publishing a similar critique of spending plans and out-turns in the UK would, it seemed to me, provide an opportunity to analyse the rationale for particular spending levels, the relationship between different programmes, and the priorities between them. Reinforcing the case for such a publication was that the mid-1970s saw a succession of economic crises. These crises called into question the central assumption that had shaped the post-1945 welfare state: that economic growth would finance the growth of social spending, a point to which I return below. With colleagues, I therefore produced three such reviews (Klein, 1975; Klein et al., 1974; 1976). This exercise taught me that the NHS was in no way privileged in the competitive political struggle for resources simply because "health care" as such was so self-evidently a good thing. Given limited resources, I argued, "one criterion for allocating them ought to be the ability to set objectives for their use, to secure the implementation of policy aims, and to check progress". In short, the NHS needed targets against which progress could be monitored: absent such targets, investing more money in the NHS was simply an act of faith, bread on water.[1] Subsequently I was able to develop some of these ideas as a Specialist Adviser of the House of Commons Expenditure Committee.

A similar theme emerged from a study of Community Health Councils which my colleague Janet Lewis and I carried out (Klein and Lewis, 1976). CHCs had been invented as part of the 1974 reorganisation of the NHS to introduce an element of local participation or representation. As part of this study, we surveyed CHC members and their activities. All this is now of historical interest only. Still relevant, however, are the somewhat sceptical conclusions we drew about the new institution from our analysis, given that the 1970s rhetoric of citizen and consumer involvement has had a second coming in the new millennium. First, we pointed out how difficult the notion of "representativeness" was, given the heterogeneity of the interests supposedly being represented (a lesson seemingly forgotten by the architects of foundation trusts). Second, we

argued that CHCs were likely to be ineffective as instruments of accountability. Anecdotal information about local services could be no substitute for a systematic analysis of the NHS's performance. Hence, we concluded, the case for a National Health Services Audit Bureau "which would carry out an on-going critical assessment of the NHS and report annually on the state of the system to Parliament": step forward Sir Ian Kennedy.

The reason for quoting the work we were doing in the 1970s – raising new questions, anticipating some later developments – is not to engage in self-congratulation, far less to claim that our ideas influenced later policy (although re-reading our publications did induce a certain sense of smug self-satisfaction in me when writing this chapter). It is, rather, to indicate the intellectual dividends that may flow from adopting a public policy approach – drawing on a variety of disciplinary sources – as distinct from coming from an exclusively NHS perspective. Looking at the references in our study of CHCs, I note that we drew on political scientists and theorists like Hanna Pitkin, Bernard Crick, and A. H. Birch (though, strangely, not Albert Hirschman, a later discovery), as well as the Webbs and G. D. H. Cole. It is also, perhaps, a reminder that a sense of history should be part of any public policy analysis, given the tendency of policy makers to persuade themselves that they are in the immaculate conception business when in fact they tend to be resurrection men and women..

I also used my time at the Centre to polish up my academic credentials in other ways. There was, I discovered, a role for a go-between two worlds. On the one hand, there was the world of the NHS, which at the time was largely insulated from the wider policy debates about how to manage public resources and organisations. So I wrote extensively in the BMJ, whose courageous and innovative editor, Stephen Lock, took the view that his medical readers should be exposed to a non-medical critique of developments in the NHS. On the other hand, there was the academic world involved in studying the policy debates about managing resources and organisations, but with little interest in the specific problems of the NHS and the challenge of dealing with a powerful profession. Astonishingly, Harry Eckstein's study of the early years of the NHS, Pressure Group Politics (Eckstein, 1960), had not sparked off any interest or imitators in either the political science or the health care academic communities. So I began to publish in political science journals (Klein, 1974), and have continued in my role as an intellectual middle-man ever since.

The role of middle-man, or go-between, has another dimension. Policy analysis requires more than a command of the academic literature and the ability to devise methods for testing theories. It also requires an understanding of the universe of policy makers: of the way in which they think about problems and solutions. Hence the importance of engaging directly with policy makers of all kinds – politicians, civil servants, NHS administrators – and at all levels. For

journalists this is, of course, a truism: as a journalist I had been used to the notion that if one wanted to talk to a Minister or top civil servant, one invited him or her to lunch at a good restaurant. But for academics in the 1970s, it was not so (things, fortunately, have changed much since then – though not, alas, to the extent that research funders are prepared to pay for lunches at good restaurants). Some of the best books about British Government had been written by North Americans who did not share the inhibitions of UK academics about charging into Whitehall and who, as temporary residents, were also seen as less threatening by politicians and civil servants. Eckstein's Pressure Group Politics was one example, but there were plenty more: a study of the Treasury by Hugh Heclo and Aaron Wildavsky (1974), and Samuel Beer's (1965) Modern British Politics, as well as a succession of books by Richard Rose.

Fortunately, the Centre for Studies in Social Policy saw itself as providing, among other things, a bridge between policy makers and academics. It had a regular programme of seminars and a hospitable lunch table. It also had among its Fellows two future Ministers, one Labour and the other Conservative, as well as others who were to make their careers in the civil service. It thus provided a stimulating environment for me, and it was while I was at the Centre that I began my programme of interviewing past and present Ministers and civil servants involved in making policy for the NHS, as well as digging into the files at the Public Records Office, which provided the raw-material for what was eventually to become The Politics of the NHS (Klein, 1983). But long before that was published the Centre had dissolved and I had become reincarnated yet again, this time as Professor of Social Policy at the University of Bath. Step by step, I had gone up in the world – from Social Class II as a journalist to Social Class I as a professor, according to the Registrar General's classification. Clearly the Registrar General was insulated from the world in which academics were actually living by 1978, let alone failing to anticipate the trends of the next few years.

The academic years

Not only were the universities in trouble by 1978 when I took up my post (budgets, like academic salaries, were being squeezed). So, too, was the post-war welfare state. I had insisted on the title of Professor of Social Policy as distinct from that of Professor of Social Administration (the first, I think, to make this change), because I thought it important to emphasise that my interests were wider than the conventional concern with the delivery of welfare services. I hoped in particular to continue to work on public expenditure with Cedric Sandford, Professor of Economics in the School of Social Sciences at Bath, the man mainly responsible for my appointment. In the event, day to day academic pressures prevented us from doing so, but we always remained close colleagues

and good friends: Cedric did not share the belief of so many of his economist colleagues that theirs was the only social science discipline that really mattered. However, trying to build up a social policy department from scratch and devising courses, forced me to take a larger view of the welfare state than I had done previously. By 1978 it was clear to me that the assumptions which had shaped social policy and the academic literature since 1945 no longer held. There was a need for an across-the-board reassessment of policy, including policy towards the NHS.

For most of the post-war period, the welfare state expanded on the dividends of growth. Even though Britain's economic growth in the post-war period was relatively slow, it allowed politicians to increase spending without curbing private consumption. In the 1970s, economic crisis whipped the ground from under the feet of politically costless altruism. In doing so, it also undermined – so I thought – the assumptions which had shaped UK academic writing about the welfare state. From T. H. Marshall to Richard Titmuss, there had been the (usually implicit) assumption that there was something inevitable about the development of social citizenship, as the former called it, and in the creation of the welfare state. The post-war welfare state was seen as a great, though imperfect, institution. It only remained to build on this achievement by filling gaps and remedying weaknesses. In the event, the academic children of the welfare state – the departments of social administration – specialised in producing critical studies of social problems. Titmuss himself became an iconic figure with his advocacy of altruism and the role of social policy as an integrative force in society. But what appeared to be lacking was any sort of analysis of why, despite the demonstrations of shortcomings and appeals to the conscience of the nation, Governments (both Labour and Conservative) failed to live up to the expectations of the social administration community. Why did the academics condemn themselves to perpetual frustration and to chronic indignation (long before Mrs. Thatcher came along) at the failure of politicians?

The answer, I thought, lay in the failure to examine the economic, organisational and political dynamics of the welfare state. To see the welfare state as a project for achieving equality and social justice – as many of those writing in the social administration tradition were inclined to do – was not only being false to history. It also overlooked the multiplicity of (often conflicting) policy objectives embodied in the various programmes, the nature of the constituencies being served by them, and the interests of those working in them. Some of these issues were being raised towards the end of the 1970s by an increasing influential Marxist school of academics who, rightly, argued that the welfare state was the product of political conflict, rather than moral consensus. But they also argued, wrongly and in dreadfully turgid prose, that what they called the crisis of the welfare state reflected specifically the "contradictions" of capitalist societies. As

against this, it seemed to me obvious that all societies – whether capitalist or communist – faced a tension between meeting the needs for legitimisation (social services), capital accumulation and consumption (Klein, 1993). The real question was whether they had political institutions capable of managing this tension. In the event, it turned out that the capitalist societies did have this capacity while the communist regimes did not – and collapsed.

Starting from this diagnosis, my interest in developing a research programme at Bath was in studying the evolution of the welfare state in response to the pressures on it. But not only were the pressures on it increasing. The economic and industrial environment was changing, and with it social structures and social attitudes. The industrial/ producer society was becoming the service/consumer society. Thatcherism to my mind was as much a response to these changes as an ideological programme: Mrs. Thatcher rode the waves rather than creating them. The instinctive reaction of traditional social administration academics was to act as a lobby for the status quo. I saw no point in joining a Society of the Preservation of the Welfare State. It seemed to me that if there was indeed to be a crisis of the welfare state, then it would derive from a refusal to consider adaptation in the light of new circumstances. In the outcome, the welfare state has indeed adapted and survived in Britain, as in other capitalist societies, in surprisingly good shape, though academic debate continues about the extent to which adaptation can be seen as transformation (the conclusion usually depending on semantic politics; i.e. the definition of the two terms).

One of the adaptive changes of the 1980s was the emergence of the regulatory state, as part of the wider movement towards the introduction of market mechanisms within public services. Accordingly, with my colleague Pat Day, I started a programme of studies on regulation; i.e. how central government controlled services which it did not produce. Starting with the inspection of social services (Day and Klein, 1990), we went on to study the regulation of social housing (Day and Klein, 1993) and of residential care for the elderly (Day et al., 1996). In turn, studying regulation linked up with a previous interest in how to define the performance of services like the NHS, for regulation assumes a notion of what an adequate performance is. Accordingly, we carried out a study of how different kinds of organisations – both public and private, ranging from the NHS to Sainsbury's – measured their performance (Carter et al., 1991): an approach based on the assumption that only a comparative study could establish whether there was anything special about the NHS (there was, notably a multiplicity of objectives and criteria for meeting them which led to prolixity in devising performance indicators). A similar assumption shaped a study of accountability in five public services (Day and Klein, 1987). In this, we tested the widely held notion that elected board or authority members would be more effective than nominated ones in calling service providers to account. In the

event, the notion did not stand up. Not election but the nature of the services, and the professions providing them, made the difference. The non-elected members of water authorities, it turned out, were the most confident in exercising control, while also seeing themselves accountable to consumers.

Engagement with the world of social policy academics, and the need to design student courses, also forced me to dive further into the literature dealing with the concepts which provided the currency of evaluation in that community. Like everyone else, I was influenced by the work of John Rawls, Michael Walzer and Brian Barry, among others. But my main guide was to be Albert Weale, because of his ability to apply abstract ideas to specific social policy issues. It was an immersion that was to prove very helpful when turning to health care policy issues, for it taught me, first, that most of the concepts were extremely complex and, second, that there might be conflicts between desirable aims. For instance, Douglas Rae's (1981) Equalities illuminated for me the many ways in which the concept of equality could be interpreted. Similarly, there might be trade-offs between different evaluative criteria: putting a high value on local democracy, for example, might mean the acceptance of apparent inequities in the use of resources.

These were fairly simple-minded notions to incorporate into the analysis of health policy, but, strangely, they tended to be seen as threatening by many of those whose intellectual universe was defined by the NHS and population health. To suggest that there might be other aims of policy beyond reducing health inequalities was seen as a betrayal of the true faith. Worse still, sceptical of the consensus that the NHS was short-changing the working class, a statistician colleague and I analysed the General Household Survey's data on the use of GP services, controlling for self-reported morbidity. We found, shockingly, that in fact there was no middle class bias. In this respect, at least, the NHS appeared to score high on equity (Collins and Klein, 1980). It was a conclusion that brought an outraged reaction from many in the academic public health community. To suggest that things might be better than had been thought was to strike at the heart of a community which made its living by demonstrating inadequacies. Happily, subsequent analyses confirmed our findings, but the episode taught me much about the relationship between theology and science and the way in which the former can drive the latter.

Conflict of a different and more constructive kind came while exploring another policy theme: rationing. The rationing of scarce resources seemed to be the inevitable common characteristic of all public social services when capped budgets met uncapped demand. In this respect, the NHS was no different from social services, housing or discretionary income support payments. There had been a spatter of books published in the 1970s – Michael Cooper's Rationing Health Care (Cooper, 1975) and Ken Judge's Rationing Social Services (Judge,

1978) – but it was not until the mid-1980s that the academic debate took off, largely following the publication of Henry Aaron and William Schwartzs' (1984) The Painful Prescription, which prompted the first of my articles on the subject. I was to follow this up with many more articles and, eventually, a book (Klein et al., 1996). It was this line of work helped to define for me – in a series of vigorous encounters with Alan Williams, in the flesh and in print – the nature of policy analysis as distinct from economics.

Ranged on one side of the debate was what might be called the emerging policy analysis community. By the start of the 1980s, a new generation, led by David Hunter and Chris Ham, had appeared in the health care arena. For example, Hunter (1980) published his Coping with Uncertainty: Policy and Politics in the NHS. Interestingly, the foreword was written by Raymond Illsley. Raymond was not only the institutional father of medical sociology in Britain, but also, as chairman of the Economic and Social Research Council's Social Affairs Committee, he was hugely influential in shaping research policy and practice. In his retirement he joined my department in Bath, bringing with him much experience and wisdom. For Hunter, Ham and myself, rationing in the NHS was an interesting phenomenon to be explored and explained in terms of the interests and perceptions of politicians and the medical profession. From this perspective, implicit rationing – veiling the decision-making criteria and process – seemed entirely rational. Not so, however, for the economists, led by Alan Williams. For them, rationality was defined in different terms: it meant a search for technical solutions (QALYs; public opinion surveys; data about effectiveness), that would dispel the miasma of muddling through. The debate continues unresolved.

The introduction of the so-called internal market also provided me with illumination about the relationship between policy analysis and other academic views of the world. I had been greatly impressed by Alain Enthoven's monograph advocating the creation of a mimic market within the NHS (Enthoven, 1985), not that I was a convinced marketeer by conviction. But I shared Enthoven's analysis of gridlock in the NHS. I was therefore sympathetic to the Thatcher Government's 1989 reforms (note, though, that Ken Clarke denied having been influenced by Enthoven when I interviewed him: a warning to academics that their ideas are likely to be influential only when policy makers have appropriated them as their own). Here I found myself in a small, intimidated minority in the social policy and public health communities, in being willing to analyse the Government's programme as an interesting experiment. Interest was seen as betrayal, an attitude that was to change only slowly as both the expectations of the proponents of change and the fears of the opponents proved to be wildly excessive.

The other conclusion I drew from this episode, in trying to define policy

analysis (in my sense of the word) by way of opposition to other academic approaches, was that the practitioners of the so-called dismal science are in fact idealistic optimists. Economists tend to believe that good ideas will inevitably earn their keep in the world: given the right prescription, the patient will recover. In contrast, policy analysts tend to believe that no idea is better than its implementability: in short, everything depends on the patient. In the case of the internal market, the intended effects were not achievable: Ministers did not want to see hospitals going bankrupt, adequate information systems were lacking, the medical and managerial cultures of the NHS were hostile. Economists often see the attitudes of policy makers, bureaucrats and professionals – the way they define their interests and the characteristics of the institutions – as perverse obstacles. Policy analysts see them as the evidence required to establish whether a "good idea", elegantly derived from theory, may in practice turn out to be a bad one because the conditions required to make it work either do not exist or are so stringent that they may in turn have damaging effects.

Epilogue

In 1997 I retired from Bath, determined to retire also from writing about health care. Perhaps, I thought, it was time to move onto another subject, such as the politics of higher education. In fact, I never moved on. A combination of sunk intellectual capital, plus the never-ending capacity of policy makers to come up with new policy initiatives and to recycle old ones, kept me at it. I continued to explore the same issues, if in a changing context, that I had been exploring in previous decades: trying to give meaning to worn out, promiscuously used words and phrases like democracy in the NHS, public participation and accountability, as well as going on with my research interests in rationing and regulation.

Another reason for my continued activity in the health policy arena was that, on retirement, Robert Maxwell invited me to join the King's Fund Institute. Robert had launched the Institute some years earlier in the belief that there was a need for independent analysis, free from the constraints of an academic environment (like teaching and scavenging for research grants) and able to scan the policy environment of the NHS. The Institute provided a stimulating but short-lived environment. Robert's successor liquidated it. The King's Fund has yet to recover the intellectual authority it enjoyed under Robert.

It is worth noting emphatically, in conclusion, the nature of the contribution made by Robert Maxwell and other foundation directors. Certainly my own work would have been impossible but for the grants I got over the years from the King's Fund, the Nuffield Trust and the Milbank Foundation and the encouragement of their directors: Gordon McLachlan and John Wyn Owen at

Nuffield, and David Willis as editor (by far the best I ever encountered) and Dan Fox as chief executive at the Milbank. But my experience was no exception, and the reason, I think, is that foundations – in contrast to research councils, let alone government departments – can take risks. They can speculate on the stock exchange of ideas, and in doing so, they can identify new themes, new challenges and new talent.

Does my career prompt any general reflections? Albert Weale once described me in conversation as an essayist in the 18th century mould. I don't know whether this was intended as a compliment – possibly he simply meant to note that I am a sprinter not a long distance runner in my writings and that I am rather theory-deaf – but I certainly took it as one. If anything links my different careers, it is a belief in rational argument and a distrust of all theologies (academic as well as religious). The role of the intellectual in health care, I believe, is to chip away at conventional wisdom and to challenge the clichés of policy discourse and academic theory, and not confuse his or her role with that of the policy maker: analysis not advocacy, diagnosis not prescription. And in policy analysis, the best starting point is, I believe, a degree of pessimism. The notion that policy can be optimised, that benefits can be maximised and so on, is a nonsense. All policies will have perverse, unexpected results, so the best form of policy making (and here, dangerously, I am on the edge of prescription) is that which accepts the inevitability of failure. If it accepts that prospect, it will be ready to change course, experiment and try again. We should not, therefore, search for perfect institutions or policies, but should rather look for adaptability and flexibility in the means used to pursue our multiple and often conflicting goals. A sentiment that would not have gone down well in the 18th century, and probably will find few takers in the 21st.

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Notes

1 A conclusion which still holds today, when mentioning targets tends to induce apoplexy in otherwise normal people; the question of how many, and what kind of, targets are appropriate is, of course, another matter.

10

Seeking somewhere to stop

Jennie Popay

How to begin?

As I was preparing to write this chapter I saw a piece in a newspaper by an 11 year old girl reflecting on her forthcoming move from primary to secondary school. She said that she liked writing and although she found beginnings hard she just carried on because she always knew what was going to be in the middle. Reading this, I realised why I was having difficulty beginning this piece: I wasn't sure what the middle would look like.

One problem has been my uncertainty about the nature of an intellectual autobiography, as opposed to 'just' any old autobiography. Basically, I suppose it must involve an account of, and reflection on, the relationship between a life course and the development of ideas. But, whilst this provides some clarification of the task at hand, it presents two much trickier problems – for me at least. First, assuming what is required is an account of the development of my intellectual capital in the context of other people's ideas, then which specific ideas in the health domain could I legitimately claim to have shaped, and what would be the nature of these claims. Second, how should I locate the development of my ideas within a biographical context? Time is the obvious (though not necessarily the only) biographical rubric, but how is time to be divided up? Which points, periods or events in time are to be given particular salience in my story?

One thing I am sure about is that story telling is the nature of any biographical project. So maybe the main purpose of the story I am about to tell is to weave personal experiences into meaningful episodes to provide a description (if not an explanation) of my intellectual journey to date. At this point I am reminded of a poem by Alice Walker called 'Moody' (Walker, 1991), which speaks of a restless pursuit of 'somewhere to stop'. This, I feel, has characterised my life course so far – both intellectual and personal. From this perspective my biographical story is perhaps best represented as a series of episodes involving very different experiences and influences. Constructing a meaningful narrative across these episodes is quite a challenge, but I think it is possible to identify some enduring threads that have led me to where I am now.

So, I have a beginning and a structure – of sorts – to help me move on. Interestingly, in the process of getting here, I have also inadvertently reached the point where I will end – my current interest in how people's 'stories' of lives lived in particular places can contribute to our understanding of the genesis of health inequalities, and can help us to develop more effective ways of intervening to reduce these inequalities. But that is to miss out the middle of my story.

Episode 1: life as a Scally

I feel I need to begin with my teenage years as a 'Scally' in Salford in the North West of England in the 1950s and early 1960s. For readers who do not know the word, Scallys are the young men and women who 'hang out' on the street corners of our towns and cities, with their hoods drawn low over their eyes and hands pushed deep into their pockets. I imagine that my friends and I were regarded by many with the same distaste and wariness as these young people are today. Going back that far – over 40 years – means that the memories I can draw on are more fragmentary than those I have of more recent episodes. But these early years seem to me to be pivotal in shaping my research interests.

We were all poor, living on means-tested benefits with those pink free school meal tickets setting us apart (at least we saw it that way) from the majority of kids with the yellow ones. Our dads drank too much and our mums were too busy surviving to worry about us (or so it seemed). We lived in a place the world appeared to have forgotten and we regarded it as a dump. Once, I remember Salford hitting the headlines for being at the top of a national league table – as the most polluted place in England. Generally, however, the place in which I lived had no particular salience for me at that time. Since then I have discovered that Salford has earned a place in the history of public health as the first city to introduce play streets and to implement the Clean Air Act (which may well have improved my life expectancy). With hindsight, I think that the most interesting thing about my friends and I was that we had all been publicly branded failures by the eleven-plus, and were attending a brand new secondary modern. We had a lovely building and, although teachers were a bit thin on the ground for some subjects, like maths and science, they were always available to teach the 'important' things – woodwork for the boys and domestic science for the girls. This experience equipped me with high level skills on the sewing machine and ironing board – skills I have never lost but rarely use.

It was, however, the domestic science teacher – a sharp tongued no-nonsense Scot called Mrs Stewart – who decided to coach the first cohort of students at our secondary modern through 'O' levels. Clearly, she saw potential that the eleven-plus process had not. I think there were ten of us in that first group – within ten years four of these young people would be dead, perhaps a reflection of the health impact of disadvantage that passed me by at the time. I think we all did quite well given the circumstances. I got five 'O' levels – failing maths but passing domestic science.

Despite this early success, I do not recall there being much optimism amongst this 'O' level group – in contrast to worlds apart from ours, in which the 'end of ideology' was being trumpeted, our friends were enjoying the music and other attractions of the 'swinging sixties', and labour markets were buoyant. I seem to

remember we talked a lot about getting out of Salford, but had no clear ideas as to how this was to be achieved. Our 'O' level group was being encouraged to stay on at school and, for the girls, primary school teaching or nursing were trailed as the golden opportunities awaiting us. We were all offered a 'choice' – to join the sixth form in a local Grammar School or to go to the local technical college. There was a row at home, and I was under some pressure to leave school and earn money, but thankfully my mother eventually supported my decision to go to the local technical college.

In some respects this could be said to have been a disastrous decision. After two years, I sat three 'A' levels and failed two, gaining a pass grade in British Government. This was no surprise to anybody, least of all me. Looking back I think I lacked some of the life skills necessary for exam success. I worked part-time in a range of unskilled low-paid jobs whilst studying and I was unable to organise myself in the unstructured environment in the college. The highlight of these two years – providing a major distraction from study – was my winning the competition to be Manchester Universities and Colleges Rag Queen. This involved a cash prize of £250 (a fortune to me at the time), a great night out at the Rag Ball wearing an expensive gown, and being crowned by a famous pop group (the Drifters I seem to recall). It was an introduction to a social world that I lost no time in exploring.

I do not doubt that I would have done better at 'A' levels had I gone to the Grammar school – certainly those in my 'O' level group who chose this route did – and I might well have then gone to teacher training college. But the time at Salford Tech set me on a much more exciting path. My year as Rag Queen made me realise that not only did I enjoy the public stage, but I was good at it. More importantly, some of the people I met, in particular David Roberts, a young lecturer in British Constitutional History, and the disparate group of students studying his course (including a minor aristocrat whose presence in Salford has always puzzled me), allowed me to envision previously unimaginable futures. How to make them real was the problem.

My route, from Salford Technical College to exploring the contribution of lay knowledge and in particular the window this knowledge offers on the relationship between people, place and time in health inequalities research, has not been linear. It has depended as much on luck and the good graces of others as it has on deliberative action on my part – factors neglected in research on pathways out of disadvantage. But I believe there is, never-the-less, a strong connection between my time as a Salford Scally and the ideas that shape my work today. Salford – the 'Classic Slum' (Roberts, 1973) – is a place where the 'hidden' and not so hidden injuries of class are inflicted (Sennett, 1977). These injuries continue to reduce the life chances and shorten the life course of many people, and they are imprinted indelibly onto my own biography. My contemporary

interest in better understanding the failure of local and national governments to deliver sustainable improvements in the social and material environment of our most disadvantaged areas, despite wave upon wave of regeneration initiatives, are also linked to my biographical connections with Salford. Those years also shaped my politics. Whilst I do not think I am a 'moody' woman, to return to Walker's poem, I continue to be an angry one, despite my advancing age, a characteristic that is not always well regarded in academia. My experience in Salford sewed the seeds for my later involvement in feminism and socialism, which has in turn shaped both the focus and nature of my research, including a desire to ensure, as far as possible, that it has some practical relevance. But there were a couple of detours before I got there.

Episode 2: down in the southern hemisphere

So, there I was with five 'O' levels and one obscure low grade 'A' level, desperate to get out of Salford and poverty. There didn't seem to be a lot of options, but I was adamant that I would not go to teacher training college. Another fragment of memory highlights the serendipitous nature of my life course. I remember one night in the pub meeting a young man who was full of stories of his time with VSO in South America. I must have thought I had nothing to lose by applying and at least it would get me out of Salford – so I applied and joined the last cohort of unqualified volunteers. This particular gate to a better life shut firmly behind me, as poorer nations rightly demanded that volunteers should have higher level skills and knowledge than I took with me. I spoke only English (and probably didn't do that particularly well) and had no practical qualifications. So, I was sent to Uganda in East Africa – where English was widely spoken – to teach in a primary school at Nyenga Leprosarium, about ten miles outside Jinja, a small town sited where the River Nile joins the northern shore of Lake Victoria.

   I stayed in Africa for five years. The first two were at Nyenga, where I eventually ran the primary school (with pupils ranging from 5 to 75) and worked weekends in the small hospital attached to the Leprosarium. These were my first non-patient encounters with health professionals: an eccentric polish dermatologist, a very elderly paediatrician from Harrogate (by far the poshest person I had ever met, but also one of the most dedicated), and two nurses from Eire. I experienced the first year of Ide Amin's brutal dictatorship, but eventually fear led me to move to Kenya, where I worked at a Salvation Army school for blind children and then moved on to run literacy classes for women. On leaving East Africa I travelled by land to Cape Town, visiting Smith's Rhodesia and apartheid South Africa.

   In Africa I saw how the legacy of Empire shaped social structures and

relationships along racial, gender and class lines. The sisters of the Franciscan Order that ran the Leprosarium rarely left the compound and mixed with residents only on a formal basis. Indeed, the historical separation of the adults and children with leprosy from the rest of us was rigidly adhered to. These nuns provided domestic services for the Irish priests living in the local seminary some three miles away, who engaged much more actively with the social life in Jinja, and Father Tom regularly took me with him to the cinema and drinking, much to the nuns' disgust. In turn, the black nuns in the 'Little Sisters of St. Francis' (who were not allowed to join the main Franciscan order) provided domestic services for the white nuns and me.

The 'civilian' nurses, doctors and I were allowed to use the facilities at the Jinja Club – swimming, sailing and drinking – the membership of which was entirely white. Here I met for the first time old colonialists who had chosen not to leave when Uganda became independent and whose paternalistic form of racism perplexed me. There were also new colonialists – many of them technical assistance staff employed by overseas governments and international aid agencies – whose racism seemed somehow more visceral. I sometimes wonder what would have become of me if I had been accepted into this social milieu – whether I too would have become attached to the luxurious conditions in which these white people lived. Who knows? Thankfully, my Salford roots were too apparent and I never was accepted on equal terms, so I didn't have to face those particular moral dilemmas.

A critical event in my life during this period was meeting Ian Popay – who I was married to for four years. Ian was a biologist working with the British Government and he – like Mrs Stewart in Salford – supported me in the pursuit of formal qualifications. I studied for three more 'A' levels by distance learning through Wolsey College (my only claim to having 'attended' an Oxford college, which I must admit to having used somewhat disingenuously on a few occasions). The subjects – biology, geography and economics – were chosen for no particular reason, other than that they were ones in which my 'tutor' felt most confident. This, plus my own teaching experiences, provided yet more examples of the perverse legacy of empire. For example, I taught Ugandan students studying for formal qualifications about the influence of the Roman Empire in Europe (a continent they could only imagine); whilst I had to have a frozen dog fish shipped out from the UK in the diplomatic bag so I could get the appropriate dissection practice for biology 'A' level.

I got the qualifications – two grade A's – unfortunately missing the biology exam due to a misunderstanding over the timetables. However, despite my grades I failed to be accepted at a UK university (this was before the days of inclusive policies and mature students), and so applied for universities elsewhere. Although not my first choice, I accepted a place to study geography at Massey

University in New Zealand, because this was where Ian got a job. The last time a turn in my life course depended on following a man.

So Africa opened the door to higher education. But more importantly, or so it has always seemed to me, during this period I was knowingly exposed to the resilience and creativity of 'ordinary' people living in extreme poverty, often with the added disadvantage of having deeply stigmatising and disabling diseases. I also witnessed extraordinary individual achievements. For example, two orphans from Nyenga went on to University (only to be slaughtered later by Amin's thugs), and some of the women I taught to read and write set up their own successful haulage company, initially moving rice from a local irrigation scheme to the nearest mill. These experiences certainly made any problems I thought I had look readily resolvable – a perspective that has served me well. But they also left me with an enduring interest in the nature of the knowledge and expertise borne out of everyday experiences and how it might help us find solutions to the most intractable of social problems.

After leaving Africa I spent five more years in the southern hemisphere, living in New Zealand. For three years I studied at Massey University, where I obtained a first class degree. I then worked in various jobs for another two years. The boredom of my first post – measuring pebbles on beaches as a research assistant – possibly explains why I didn't pursue a career in physical geography.

My time as an assistant town planner was more significant. My boss, Peter, was an idealistic town planner coming to the end of his career and Auckland was, and still is, the largest Polynesian city in the world. The majority of Islanders were illegal immigrants, and therefore not accessing social security or other services and living in very poor conditions. Peter worked tirelessly to address the issues of inclusion and accessibility and had a strong commitment to democratic methods – not particularly common in town planning at the time in either NZ or the UK. He was strongly influenced by a small book published in 1971, entitled "The Responsible Society in New Zealand" (Sutch, 1970). It was written by William Sutch, who had been a public servant since the 1930s in New Zealand and with the United Nations. I still have the copy that Peter gave me to read and from memory, reinforced by the heavy annotations still visible in the margins, it had quite an impact on me.

Here was a powerful critique of the welfare systems created since the 1930s. It drew heavily on the writings of Richard Titmuss (although, with hindsight, clearly not as well written). New Zealand – widely perceived to be the egalitarian paradise – was revealed as a deeply divided unequal society with an increasingly residual and selective welfare system, a situation that Sutch argued impoverished everybody. The solution, for Sutch, included: designing social security systems that distributed 'social rights without stigma'; recognising that social security expenditure is 'at the very minimum…an investment'; focusing

resources on prevention rather than 'ambulance' work; and the 'positive provision freely to all of education, health and full opportunity for personal development in society'. There was also much that was critical of the medical profession, including their lack of accountability and their lack of knowledge of the wider social determinants of ill health. One heavily underlined passage obviously impressed me in this regard:

"The traditional social position and strong trade union activities of the medical profession and their role in the physical illness of the individual has put out of focus the essential contributions to health that are made and could be made by others and by the social and physical environment" (Sutch, 1970, p. 106).

Sutch argued for a 'creative health service', organised around social services centres emphasising social medicine and focusing on the health of the community. Doctors would not be in private practice, but members of multi-professional teams and the centres would have to have strong community participation in planning and control. Heady stuff – at least for me at the time.

New Zealand gave me the opportunity to obtain a first degree and, serendipitously, my post as an assistant town planner introduced me to the world of social policy. This started me on a path that led me back to England, and eventually into research on health inequalities and public health. Somewhat incidentally, life in New Zealand also firmly established my feminist politics. I still remember how angry I was when I was told that as a married woman without a paid job I couldn't open my own bank account, and later as a divorced woman I was ritually subjected to the humiliation of having a spare man provided for me on all social occasions.

When I was working in town planning I had begun to apply for postgraduate work outside New Zealand, having decided that it was not for me. I had been offered a place on an MSc course in Environmental Planning in Canada. However, I recall being unsure about this move – partly because I wasn't sure I wanted to move to Canada and partly because I was becoming more interested in the social, rather than the environmental, aspects of planning. Before accepting the Canadian place I travelled back to the UK to visit my family, and whilst there went to hear Peter Townsend speak at the LSE about his ambitious survey of poverty in the United Kingdom. And that was it – well, probably it was more complex than that, but listening to Peter did convince me that I should shift my focus, and I registered to do the relatively new MA in Social Service Planning at Essex in 1977.

Episode 3: in the capital city

Essex was an enormously stimulating environment. As students we were exposed to innovative and radical thinking from the academics contributing to the

course – Peter Townsend, Adrian Sinfield, Stan Cohen, Michael Mann, Duncan Gallie etc. – who have made major contributions to theoretical and empirical developments in social policy and sociology. They were also, in the main, academics who engaged actively and enthusiastically with the worlds of policy and practice – an example that I was keen to follow. They were, of course, all men, but that is another story.

The Essex course defined 'social services' in the same way as Sutch had done: to cover all aspects of the 'welfare state', rather than only the domain of social work, although after I left I believe that the course did narrow its focus somewhat to become a formal Certificate of Qualification in Social Work. Sutch had compared New Zealand unfavourably with other countries and seemed to believe that the radical developments in social medicine and welfare he espoused were well advanced in the UK. I quickly realised that this was not the case. I had come back to the UK after being away for more than a decade, to experience an academic community focused on the 'crisis in the welfare state', and on the shifting boundaries between the state, the family and welfare; to a political debate about the most appropriate strategies for addressing the problems of 'welfare' and supporting economic growth; and to a personal environment in which the consequences of fiscal policies were increasingly evident in raising levels of unemployment and poverty amongst my family and their friends in Salford. I was determined to contribute to these issues in some way and began to look for work.

I applied for my first 'proper' jobs in 1978 and I was offered two – a permanent post as a researcher with Yorkshire Television in Leeds, and a fixed-term contract research post with the Unit for the Study of Health Policy (USHP) at Guy's Hospital in London. This was a really difficult decision. These two very different posts spoke to two equally strong facets of my developing interests. I have always enjoyed the detailed work of 'systematic enquiry', whether through policy analysis or formal research. But equally I enjoy contributing to and promoting public debate about the nature and direction of policy, and I always get a real buzz from appearing on TV or radio. From the beginning of my career in the UK, I had to choose between these two interests – and this has been a source of discomfort for me in most if not all of the paid positions I have held since. I chose to go to London – partly because of the pull of the capital city and partly because I thought that an academic career would have more status. I was probably right about that, but I would certainly have earned more as a TV programme maker. And then came Thatcher.

These were busy years at USHP. The small team led by Peter Draper concentrated on developing a critique of current UK health policy, focusing in particular on the shift in public health that followed the Royal Commission on the NHS with the demise of the local government Medical Officer for Health

and the increasingly administrative and hospital-based role of community medicine. The continued dominance of hospital care and the neglect of the wider environmental hazards to health were major foci of our work and I believe we coined the phrase 'make the healthier choices the easier choices'. During this time the *Black Report* was published and all but disappeared, and with hindsight it is clear that USHP failed to address the social policy aspects of the health inequalities agenda. We were criticised for this by people on the left and, as a young researcher, I remember being publicly censured at several national conferences for being politically naive. In terms of public speaking it certainly felt like a baptism by fire.

Whilst I was at USHP I met and worked with people who sharpened my interest in the interface between research, policy and politics, including, in particular, Drummond Hunter, a senior health service administrator in Scotland with a passion for 'planning for health', James Cornford, the political scientist, who was at the time Director of the Outer Circle Policy Unit, and David Hunter (son of Drummond), who worked with James. As Leverhulme funding for USHP came to an end, the future looked increasingly uncertain and I began to look for other work. I wanted to develop my interest in the research/policy interface further, and so I took a fixed-term contract post with the newly established Study Commission on the Family – an interesting move.

The Commission was run by Malcolm Wicks, chaired by Sir Campbell Adamson, Chairman of Abbey National Building Society, and included some very eminent people, including a young Peter Mandelson and the Reverend Mann – Dean of Windsor and vicar to the Royal family. I had little to do with the Commission itself, although we were always allowed to sit in on their discussions. Through Malcolm I also met and worked with other significant social policy analysts, including Jonathan Bradshaw and Chris Pond, then Director of the Low Pay Unit and a junior minister in the Treasury in 2004–5. Malcolm was an expert at using the media. Our work was regularly covered in the national press and I got to do several live spots on the Today Programme. At the Commission I developed my interest in the social and economic circumstances of female-headed one parent families, and the economic, social and health consequences of unemployment (which was rising rapidly). In my private life, I was also beginning to put my politics into action. I joined the British Society for Social Responsibility for Science's "Women and Work Hazards Group", which produced information for women in employment. We also made a well-regarded documentary, funded and shown by Channel 4, and lobbied trade unions to give higher priorities to the health hazards facing women at work. I was an active member of the Child Poverty Action Group, sat on the Board of the National Council for One Parent Families, and worked with Youth Aid, whose director at the time was Clare Short. I also acted as an adviser to Michael

Meacher when he was shadow health secretary, and to the Labour Party committee on women.

I realised later that at the Study Commission on the Family I was observing, from the sidelines, the development of New Labour in terms of: ways of working (public/private partnerships, for example, and the use of deliberative methods to develop a consensus); ideas and policies; and, of course, future ministers. At the time, I was only aware of a general sense of unease with the direction in which the Commission's policy recommendations were going, and on one occasion at the pub I told Malcolm, who was open about his wish to get into parliament, that if he was ever elected as a Labour MP I would resign from the party: something I have not quite been able to bring myself to do – yet. Inevitably, the funding base for the Commission became increasingly insecure, but, more importantly, the contradictions between my political beliefs and the Commission's public positions became too uncomfortable. So I moved again.

This time the fixed-term contract was only half-time – as a lecturer on the new Open University (OU) team set up to produce an innovative multi-disciplinary course on Health and Disease. Here, I was privileged to work with some very interesting and committed people including: the course co-ordinator and unsung heroine, Basiro Davey, a biologist who had an astonishing ability to cross disciplines; the eccentric, sometimes overpowering, but always stimulating course chair Stephen Rose; Phil Strong, one of the most imaginative of medical sociologist; Alastair Gray, an economist with a great love of history; and Nick Black, the first doctor I had met who was genuinely interested in social issues. U205, as the course is known to its friends, became one of the most successful OU courses ever. I believe that my contribution to this course was to widen the focus to include material on social policy in the UK, and I returned to Salford to make an OU television programme on health inequalities. The other half of my time was spent working on a project on the implications of high levels of unemployment for health and social services – my first grant as principle investigator, obtained from the Health Education Authority (HEA). This project got me my first and only mention in Hansard, when Margaret Thatcher was able to parry a hostile question on the health impact of her economic policies by announcing that her Government was funding research in this area – a very uncomfortable moment that caused me to think long and hard about ethical issues in research funding.

As these two fixed-term contracts came to an end, I obtained funding from the Baring Foundation to turn the results of the HEA research into a resource pack for service providers working with people experiencing unemployment. However, this would only fund one person, so we agreed that my co-worker would do the paid work on this project, and I moved on. This was another fixed-term contract, as a research officer working with Ann Oakley, who had recently

been appointed to her first permanent post as Deputy Director of the Thomas Coram Research Institute (TCRU). I joined a programme of work Ann was establishing with ESRC funding on aspects of family health, and conducted research on the impact of lone parenthood on the health of women and their children, and on the experience of parents in households with contrasting material standards of living.

After two years in post, and a decade after I took my first post in London, I applied for and was appointed to a permanent senior research post in the TCRU. However, and more significantly, shortly after this I had my first and only child, Thomas, ironically as a lone parent. Thomas had complex health needs and spent the first two years of our life together in London in and out of hospital. Eventually, I decided that I was making too many demands on my friendship networks, and so I sought the (almost) unconditional support offered by my family and returned to Salford.

Episode 4: the return north

It was 1991 and after more than two decades I had returned to Salford. Thatcher's health care reforms were in full swing: the purchaser/provider split was being implemented and public health was undergoing a renaissance of sorts. Health research was also in the ascendancy with the establishment of the NHS Research and Development Programme, and the evidence-based movement was taking off with the establishment of the Cochrane Collaboration. I was appointed to set up and run one of a network of Public Health Resource Centres, providing support for the newly developing purchasing authorities. The centres were the brain child of Dr Stephen Horsley, the Regional Director of Public Health. Stephen and I got off to a bad start when I insisted that my centre would have the word 'research' in its title. He was adamant that this should not happen, but my management group supported me and it became the Public Health Research and Resource Centre (PHRRC).

Soon after I took up my post, one of the four Directors of Public Health on the Centre's management group – Dr Ian Greatorex – was appointed to the Chief Executive post with Salford Health Authority. Ian became a powerful advocate for the centre both locally and nationally, a major intellectual influence on our work and a good friend. PHRRC soon established itself as an authoritative source of research-based evidence on population health needs for our local funding agencies. We also developed a national profile as a unit undertaking social science research and development work in the public health domain, and were successful in bringing in significant research funding. After three years employed by the NHS I was appointed to a chair in sociology and community health at Salford University – the only female professor on the staff and only the

second woman to ever hold a professorial position in the University at that time. I took the PHRRC with me to the University.

I was director of the PHRRC for ten years. I also spent a period as Associate Dean of Research in the Faculty of Arts Media and Social Science, and was a member of the University's research committee. During this time, I continued to pursue my interest in research on the nature and significance of lay knowledge about health and illness, and on the actions people took to 'survive' in the face of severe social and economic disadvantage. This was also the time of Thatcher's 'listening to local voices' policy – a forerunner to today's patient and public involvement policies – and the PHRRC became involved in many local initiatives aimed at involving people in decision-making, and exploring practical ways of applying research into lay expertise. We developed approaches to the research-policy interface, based on close dialogue with commissioners and patient and/or public groups throughout the research process. With the election of a (new) Labour Government, Salford became the focus of yet more waves of regeneration, and the PHRRC became involved in urban renewal initiatives, supporting evaluative research and new models of social action by residents.

I believe that the work of the PHRRC provides a number of examples of successful public/patient involvement in policy decision-making. Our research has demonstrated some of the considerable gains – measured in social, health and economic terms – to be had from involving people in both the definition of health problems and in the development of solutions to these problems, making use of the considerable expertise people acquire through their everyday experiences. The work we did contributed to commissioning decisions that resulted in the movement of millions of pounds into services that more closely reflected population health needs. We were also key players in establishing qualitative research as a legitimate part of the evidence base for health policy and practice. We initiated a qualitative research network within the Cochrane Collaboration, and then formally registered a methods group within the Collaboration that focussed on qualitative research and systematic reviews.

Paradoxically, however, whilst my energy and commitment for the health inequality field has its source in my biographical connections with Salford, and whilst my return to the city more than two decades after I had left it has served me well in terms of career advancement, work satisfaction and friendships forged, my experiences during this period also sewed seeds of cynicism and self-doubt. During the 1990s, I grew increasingly suspicious of the myriad of 'technical fixes' being developed to include patients and lay people in health related decision-making – including citizen panels, focus groups, Oregon style consultations, patient and public surveys, health needs assessments, community development and health projects and, most recently, patient and public involvement forums. Over time, I have come to the conclusion that authentic

involvement of 'ordinary' people in decisions that affect their health and well-being will only come about if there are profound changes in the culture and ideology of public services and the professions, alongside wider democratic renewal.

As a non-executive on a local trust, a commissioner with the Commission for Health Improvement and the Commission for Patient and Public Involvement in Health, I have also become deeply sceptical of this form of public service as a mechanism for increasing the accountability of public sector organisations. The Nolan principles of public life – selflessness, integrity, objectivity, accountability, openness, honesty and leadership – seem to have little to do with the reality of my life as a non-executive. Rather, accountability to sometimes self-serving civil servants, the management of seemingly endless organisational restructuring (with all the human and economic costs that involves), and the imperatives of financial accountability and risk aversion, dominate, leaving little room for 'real' accountability to the public for whatever the substantive focus of the organisation might be.

With my move from London I also rose relatively rapidly up the career escalator, and as I did so I began to experience difficulties with some of my senior male colleagues. My experience of academic collaborations across institutions has also left scars and taught me, amongst other things, that the best collaborations are built on existing relationships characterised by mutual respect and trust, not pragmatic unions of 'partners' judged to have complementary substantive interests.

Concluding comments

In 2001 I decided to step off the senior management escalator – at least for a while. My personal life was a bit complicated and ten years of running a research centre based almost entirely on soft money and feeling responsible for the employment of around twenty contract research was also taking a toll. Finally, the difficult relationships I had with some of my senior colleagues were causing me to question whether I had the appropriate skills and competencies for senior management positions. Initially, I moved to a chair in Sociology and Health Policy in the Nuffield Institute at the University of Leeds, but the Nuffield was going through major organisational change. I had two options – stay around and get more involved with the management of change, or move on rapidly – I chose the latter course and moved to my present position at Lancaster University.

Since I left Salford I have reflected long and hard on my contribution to the problems I have experienced as a senior manager and collaborator on major research initiatives. Throughout my working life I have developed and tried to maintain an ideological approach to issues, including the gender relationships

that occur within organisations and institutions, and feminism informs all I do. The modern phrases 'glass ceiling' and 'glass walls' are relevant to my experience, but the problem is about more than ceilings and walls. I have worked with powerful men who have been helpful and unhelpful, and with some who have been downright obstructive and destructive, both organisationally and personally. In our public services, which collectively are amongst the biggest employers of women in the world, it is still the case that women are much less likely than men to be appointed into positions of leadership and power. When we do get there it is hard and difficult. I have had to fight to be heard, to be listened to and to be respected throughout my career. Having worked hard to secure my positions and having the intellectual ability to achieve them, it is unacceptable to have to then 'earn' respect from male colleagues. I am not alone in being branded a difficult woman, simply for having the tenacity and chutzpah to argue my point, defend a position, and advocate for change. How easy it is for colleagues and associates to label. And once labelled it sticks, reputations precede one and the powerful males adopt the behaviour they think necessary to deal with 'difficult' women, even before the discourse begins.

Sociological research has much to say in respect of the phenomenon of people living the expectation of a label. I know that this applies to me at times. Battling the gender game in a working environment is tiring and emotionally draining. However, battle it I will continue to do, until the all too present macho culture of leadership and power sees the need – or is forced – to change. My hope is that if I am asked to write the autobiography of my older age – perhaps 20 years from now – my experience will be different. If not, that residential care home will be more discordant than necessary.

So, that is the story of my intellectual journey so far – which reminds me of one of my favourite quotes about the power of stories. This was given to me, like most of my literary references, by my friend and colleague, Gareth Williams. It is from the book by James Kelman (1994), "How Late it Was, How Late", which Gareth tells me won the Booker Prize, in spite of protestations that it was full of foul language. It certainly is that, but it is also full of breathtaking insights into social life. One character in the novel vividly highlights the role of stories in social interaction, noting that:

"…stories, stories. Life's full of stories, they're there to help ye out, when ye're in trouble…they come to the rescue, and one thing ye learn in life is stories. Sammy's head was fucking full of them."

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11

Political ideals and personal encounters

Albert Weale

Born in Brighton in 1950, I am a child of the welfare state. I can still conjure up in my mind's eye those flat, rectangular shaped bottles containing orange juice and cod liver oil, as well as recall my first operation in hospital – for the removal of my tonsils of course. My parents were quite old when I was born. They did not have much money, and they spoke of the relief from financial anxiety that the National Health Service had brought to them. So I had early exposure to the difference that the coming of a publicly-funded comprehensive health service meant to those who would otherwise have been vulnerable.

Partly because of this background, and partly because it was part of the temper of the times, I thought of health care in terms of the NHS and of the NHS in terms of the benefits of collectivisation, a view reinforced in the history I learnt at school, where the Whig interpretation seemed to have transmuted into the socialist interpretation. Instead of the steady march to the freedoms of the true-born Englishman, we had the gradual dawning of the need to tame private property and markets, consolidated by the arrival of the welfare state. My own politics during my teens and early twenties were Labour rather than new left. I took no real interest in Vietnam, did not occupy lecture theatres or classrooms, and felt ambivalent about environmental issues. I was, however, concerned about third world poverty, a concern that I took to be continuous with my concern about poverty at home. I identified myself with *Tribune* at one stage, but moved steadily towards a Croslandite position, particularly after I had actually read *The Future of Socialism* (Crosland, 1956).

These early influences were deep, and have been long-lasting. They have interacted in various ways with my academic interests in political theory and health policy. Also important have been the personal acquaintances I have made among those involved in health care research. It is surprising how like Anthony Powell's *Dance to the Music of Time* life can be, as individuals occur and recur in one's life. So my story is one that weaves together the personal and the political, at least if we take the latter to cover the study of political theory rather than the practice of politics.

Social justice and resource allocation

I was both an undergraduate and graduate student at Cambridge. After a false start on a PhD in the philosophy of religion, I embarked on a thesis in political theory. Because of my personal politics, I was active in the Fabian Society, the local Child Poverty Action Group (CPAG), and the Labour Party. I was convinced, however, that it was not just enough to espouse a political position; it was also necessary to be able to justify it to others. In particular, I wanted to provide a theoretical account of what to me seemed obvious – that all persons had a basic dignity which meant that in certain matters at least they should all share

in entitlements to a common set of goods. When I first presented these ideas in inchoate form to Dorothy Emmet, my PhD supervisor, she was taken aback by this abrupt change from my original plan of working on the philosophical theology of Paul Tillich, but with her characteristic steadiness of nerve soon settled down with me to make it work. I have always been grateful to her for her support, and the experience made me understand what commitment from one's PhD supervisor means.

The intellectual and political background to my thinking at the time was found in Tawney's (1952) *Equality*, but it had recently received – so I thought – an eloquent exposition in Rawls' (1972) *Theory of Justice*. I was also reading a lot of literature in social policy, partly in connection with my work in CPAG and partly because I found it informative in itself. Putting political theory and social policy together thus seemed a sensible way forward. Yet, this was hardly a coherent research project, as would be required nowadays. But that, perhaps, was an advantage. The established social sciences at the time were dominated either by an applied empiricism or by an abstract theoretical concern of an Althusserian kind. In their own ways, these are important pursuits, but I wanted something that was normative, intellectually rigorous, but with application to the real world. There was work in this mode, including that by Herbert Hart (1963) and Brian Barry (1965), as well as some work in applied welfare economics, but I think it fair to say that the view that there could be an intellectually coherent *evaluation* of public policy, in terms of normative principles, was generally regarded as eccentric. Coming to the issues unconventionally meant that I could look at them in a way that was free of the prevailing, and to my mind rather stifling, fashion.

I do not want to present this development as a clear, linear evolution of thinking. My working habits were (and in many respects still are) chaotic. Although I work regular and long hours, I do not work well according to plan. Because normative political theory, particularly of the applied variety, was new, I had few explicit models to follow. I do think, however, that was a better situation than the present one, when many new graduate students have to plough their way through endless, and often rather repetitious, expositions of a variety of theoretical positions. I drew on a wide range of materials, many of which I learnt were not relevant, and had to discard. The absence of any economics at degree level in my education was a handicap. My examiners wanted a number of improvements in my thesis before they would pass it; so did I, and the examiners got many more changes than they had requested.

I was helped in all of this by a large number of people. It is invidious to pick some out, but there are certain names that recur in one's life. I could discuss matters of social policy with Ken Judge and David Vincent, both of whom took a leading part in Cambridge CPAG. Also at Cambridge, I could discuss normative

political theory with John Skorupski and Richard Tuck, the latter introducing me to the work of Henry Sidgwick, who has become a life-long influence. Later at Newcastle, where I held the Sir James Knott Fellowship between 1974 and 1976, Peter Jones was particularly important in relation to my thinking about political theory. His command of the then available material was so well organised into his course teaching that it gave me confidence to think that there was a genuine sub-discipline of normative political theory rather than a collection of intellectually interesting, if potentially insoluble, problems.

Welfare economics has been a continuing influence on my thinking, despite my absence of formal training. One of the reasons why I was pleased to be offered a post as Lecturer in Politics at the University of York – quite apart from the obvious need to earn a living after September 1976 – was my familiarity with the work of some people in the Department of Economics, particularly the health economists, including Tony Culyer, Alan Maynard and Alan Williams, who focused upon applying the test of economic efficiency to the analysis of social policy. Although I thought that an exclusive focus on the possibility of making some people better off without making anyone else worse off was too narrow to be fully adequate as a basis for policy evaluation, their pioneering attempts were in many ways a model of how these things might be done.

By the late 1970s, what position had I managed to work out in relation to the political principles that ought to inform health policy? The key conclusions were set out in the published version of my thesis, entitled *Equality and Social Policy* (Weale, 1978). In that work I claimed that Rawls's veil of ignorance argument, suitably interpreted, provided the intellectual basis for an egalitarian theory of justice, and that in health care this meant that attention had to be given to the satisfaction of health care needs. However, I also appreciated that simply saying needs should be satisfied was inadequate, since there might be conflicting needs among individuals and there would not in any case be enough resources to satisfy all needs. The relevant principle would therefore be one in which the risk of unsatisfied needs was distributed equally among citizens. I inclined to the view that the relevant organisational framework implied by this account would be something like the NHS, but I did not just *assume* this. I took some trouble to argue for this position, though not as much as I should have done, as Paul Menzel (1983, pp.84–85) kindly but accurately pointed out. Yet, as a result of such thinking as I was able to do, I came to think that supply-side considerations would have an important role to play in any final arguments over a theoretically defensible account of the organisation of health care.

Retrospectively, though I was only dimly aware of this at the time, the main intellectual move I made was to think about the problem of resource allocation on the model of collective insurance by citizens themselves in relation to their health care needs. To be sure, the state had to be involved as the agent of this

collective interest, but this did not mean that a paternalistic state elite was meeting the needs of its subjects. Rather health care provision was ultimately a problem of designing a system in which each citizen who was able made a contribution to a common pot in exchange for the right to draw out resources to meet needs at a later point. The implicit model was therefore one of reciprocity rather than altruism or a benevolent welfare state. To be sure, the reciprocity had to be constrained by a concern for a basic human dignity. It could not be the reciprocity of the well-off insulating themselves from the needs of everyone else. In that sense it had to be generalised reciprocity. But in the end there was a social decision that had to be made about the needs that it was reasonable to cover out of the common pot. Implicitly, though this is not how I would have put it at the time, I was struggling for a reconciliation of what seemed the absolute demand of justice – that everyone had a life to lead that was as valuable as any other – and the acceptance that human institutions would always have to draw clear lines of entitlement, beyond which needs could not be met.

It also seems to me that these concerns sprung naturally from the way in which policy-makers thought of the dilemmas they faced in the post-war welfare state. I knew about the work of the Resource Allocation Working Party, and I had read Heclo and Wildavsky (1974, recommended to me by Ken Judge) on the politics of the budgetary process in the UK, as well as the work on public expenditure that Rudolf Klein had embarked upon at the Centre for Studies in Social Policy. As a result, health policy seemed to be about nicely calculated less or more (I did not foresee that it was to become about NICEly calculated less or more). From this point of view, the problem was conceived as one of allocating resources in static equilibrium within a stable organisational context. Thus, the two main questions were: how do we achieve the right balance between public and private expenditure, and how do we ensure, in the domain of public expenditure, that money is correctly spent? The subsequent debates about the organisational form of the NHS were unanticipated, because the relevant problems were thought to have been solved by the reorganisation of 1974. Larger questions about the evolution of institutional arrangements were thus left out of account.

Personal freedom and preventive health care

Spending time on sabbatical leave is a good way to think about personal freedom. I spent the latter half of 1979 at Yale University as a visiting scholar in the Institute for Social and Policy Studies (ISPS). ISPS was a wonderful place at that time. I was fortunate enough to be invited to participate in a Thursday lunchtime seminar on 'American Democratic Institutions', somewhat misnamed because it was really about democratic theory broadly conceived. I remember

coming out of the hour or so long discussions with my head spinning with ideas and insights, and it would often take me some time to return to work at my desk during the afternoon. The participants included Bruce Ackerman, James Fishkin, Robert Dahl, Charles Lindblom, Theodore Marmor, David Mayhew, Douglas Rae, Adina Schwartz and Douglas Yates.

Ted Marmor was to be a particularly important figure. He had recently arrived at Yale to head a new research programme funded by the Kaiser-Permanente Foundation on non-medical ways of improving health status. Ted was the first living political scientist I had ever met whose specialism was the politics of social security and health care and who also thought that you could and should apply normative criteria of evaluation to social policy proposals. It also turned out – here Anthony Powell springs to mind once again – that he was a friend of Rudolf Klein, who in *Political Studies* had recently given a positive review to the published version of my PhD thesis.

After I had returned to the UK at the beginning of 1980, Ted was kind enough to invite me to give one in a series of Kaiser lectures at Yale in 1981. Since the programme was on the subject of preventive health measures, I decided to try to pick up systematically some of the issues of paternalism and personal freedom that such measures often raise. I had read *Prevention and Health: Everyone's Business*, when it was published by the UK government in 1976. As an admirer of John Stuart Mill's *On Liberty* (Mill, 1859) as well as Herbert Hart's (1963) and Samuel Brittan's (1968) arguments for a permissive society, I knew that there were some deep issues of principle involved. Growing up in Brighton had also inclined me to a liberal view of life. Graham Greene was right in his portrayal of the town in *Brighton Rock* as a place of sinful pleasures, but I took a more indulgent attitude towards those aspects of its life. Putting all of these influences together led me to think that issues surrounding prevention and health are more complex than is often assumed.

The central problem is easy to state. Preventive health measures take a variety of forms. They may involve regulation or the use of economic instruments to alter or modify unhealthy behaviour. They may involve state intervention in the field of worker health and safety. They also obviously involve environmental measures. Many of the measures rest on the assumption that public policy makers know better than individual citizens what is in the best interest of those citizens. Yet, does not a liberal and democratic society have to presume that each person is the best judge of his or her own welfare? How can paternalistic interference in lifestyle choices be therefore justified in a liberal democracy?

This problem becomes insoluble if we define welfare in terms of the free choices that individuals make, as is the custom in welfare economics. If persons preferring one course of action to another is what constitutes their welfare, then there can be no grounds on which anyone else can override that choice to the

advantage of those persons themselves. I thought at the time, and still do, that this line of reasoning was inadequate and that more discrimination was needed if we were to do justice to the competing claims in the field. Rather than the conventional wisdom of contemporary welfare economics, in which welfare is identified with choice, I preferred to think with the older utilitarians like Sidgwick (1891, pp. 137–140) that the proposition that each person is the best judge of his or her own welfare was to be taken as a corrigible empirical generalisation. Of course we should assume in a wide variety of practical everyday contexts that each person was the best judge of his or her own welfare. For policy purposes we could not do otherwise. In any case the principle is that each person is the *best* judge, not the *perfect* judge – a distinction that Peter Jones once impressed upon me. It is quite compatible with the best judge principle to say that people make mistakes. Usually, no one else is likely to do a better job.

Usually, but not invariably. There are some circumstances in which as individuals we make choices in the short-term that are to our long-term detriment. When present sacrifices are needed in order to secure future benefits, and where those sacrifices are regular and onerous, it is easy to see how people may miscompute the cost-benefit calculus. Moreover, causal links are complex, and there are many imbalances of information between supplier and consumer, so that consumers may not fully appreciate the characteristics the commodities possess, especially those that pose risks, whether we are talking about tobacco or the composition of foods. For these reasons, although a free society will want to preserve as much scope as possible for individual choice, there will be issues and occasions on which some form of paternalism is justified if the government sees that it has any role in promoting and protecting welfare.

The way I presented these conclusions in the Kaiser lecture was via the figure of the 'liberal paternalist' (Weale, 1983). The liberal paternalist is a person who accepts that there is a burden of proof on the proponent of paternalist measures, but who also accepts that sometimes this burden can be discharged. The evidence for the benefits of restriction must be strong and well founded – ideally by experimental means. Even once this burden has been discharged, the liberal paternalist prefers the use of the price mechanism to outright prohibition. Taxing tobacco is better than banning it altogether. However, the liberal paternalist does not oppose regulatory controls when these seem particularly effective or appropriate. Thus, the liberal paternalist does not have an objection to a law requiring the wearing of car seat belts.

There was one other consequence of this interest in preventive health that Ted Marmor had sparked, namely an interest in environmental issues. Environmental protection obviously raises many fewer issues of paternalism than do measures aimed at lifestyle, although it does raise some. However, from the point of view of policy analysis, there is a significant overlap between

environmental and preventive health matters. When I moved to the University of East Anglia in 1985 and started working with Tim O'Riordan in the School of Environmental Sciences, I was able to draw on some of the lessons that I had learnt from looking at issues of preventive health. Ted Marmor and I collaborated on a paper that drew out some to the parallels between preventive health care planning and environmental protection planning. This paper had a sort of *samizdat* existence for a number of years, circulating in a draft version. Finally, Ted was kind enough to include the thoughts in his Rock Carling Fellowship lectures, published as *Fads in Medical Care Management and Policy* (Marmor, 2004).

The King's Fund: theory and practice

In the early 1980s I organised a series of ESRC-funded seminars on Political Theory and Social Policy. At one of these, Ken Judge asked me if I would be willing to serve on the advisory committee of the new health policy institute that the King's Fund was setting up and that Ken was going to direct. This invitation introduced me to the world of the King's Fund, and a close association that I maintained in various forms until 2001, when I came to the end of a five-year term of office on the Grants and Management Committee.

From my viewpoint, the value of the Fund was the way in which it created an environment in which the world of ideas could interact with the world of practice. When I first became associated with it, Robert Maxwell had started the process of turning the Fund into an institution with a unique mission. With his ability to move between academia, organised medicine and the world of management, Robert created a focal point for all of those concerned with the changes in health care inaugurated in the 1980s. Through Robert, I was drawn once again into thinking about the ethical basis of the allocation of health care resources, but this time in a more practical and institutionally complex context. In work promoted through the King's Fund, I collaborated with others in trying to work out whether it was possible to state a set of principles upon which health care could be fairly allocated (Weale, 1988). One of the great temptations of policy-makers and their advisers is that they confuse models that are useful for the analysis of health care institutions with assumptions about what will happen if changes are made in health care organisation. In particular, at that time, there was an assumption among policy-makers that, if only the right organisational incentives could be put in place, the resource allocation problems of the NHS would be solved. I learnt from Robert that culture mattered as much as organisational form and that, unless due attention was paid to professional responsibility within institutions, changes of organisation by themselves would not get to the heart of the issues.

At the time, the dominant message of the King's Fund on these issues was that the principles of allocation needed to be made more explicit if responsible decisions on allocation were to be made. Although I did not make the connection at the time, I suspect it was for this reason that Robert was not as hostile to the introduction of the internal market reforms in the early 1990s as were some others. By creating contractual or quasi-contractual relations among leading actors, those arrangements would create an institutional context within which politicians and policy-makers had to be more open with the general public about what could and could not be afforded, and this culture of openness would contribute to responsible political discussion.

On reflection, it seems to me that this emphasis upon making explicit what was implicit raises many difficult issues. From the point of view of democratic theory and practice there is a great deal to be said for explicitness and openness, particularly if we see the public provision of health services as a form of collective self-insurance. There is obviously a temptation in democratic politics, particularly of an adversarial kind like that of the UK, for politicians to promise that more service can be delivered for less money, producing the familiar rhetoric that Britain can have European levels of social provision with US levels of taxation. By contrast, if citizens are confronted honestly and openly with the trade-offs, one might hope that they will see that you don't get owt for nowt, and they might even then see the rationale for adequate funding through taxation. Perhaps there is a chain of argument from explicitness to politically accountable priority setting to better public expenditure settlements (which might not always be higher public expenditure settlements).

Perhaps. But on reflection I have come to see some gaps in this chain of reasoning. Like any system of production, the health care system is enormously complex and the efficiency of resource use seems to vary greatly. Central planners simply lack the requisite information to know which of these variations in resource use can be eliminated without losing something valuable that is not being measured. In any case, technological change makes it difficult to monitor and oversee a dynamic system. More importantly, a central part of professional motivation is the freedom to do what one regards as a good job, and this motivation relies upon being allowed some discretion as to how one goes about the job. Such discretion is incompatible with too prescriptive a view as to what politically accountable health care priorities might be.

This may sound like a counsel of despair, or perhaps a protectionist defence of professional autonomy, but it is not intended to be. It seems to me that the approach of NICE is broadly along the right lines. NICE examines particular procedures and technologies and seeks to make a judgement in individual cases as to what is cost-effective and what is not. There is a lot to be said for addressing the issues in terms of what is professional good practice rather than an

authoritative determination of what should be in the list of citizens' health care entitlements (and by implication non-entitlements). Moreover, the practice of NICE is specific. It is not aiming to determine some overall health care package, but rather to look at particular issues. Disjointed incrementalism, with an element of fudge, may be the best that we can do.

I am reinforced in this conclusion by reflecting on the work that has been done on new participatory practices in decision-making. When I chaired the King's Fund Grants Committee I was anxious that we supported experiments in new forms of public involvement in decision-making, including citizens' juries and deliberative polling. The hope was that, in calling upon the 'ordinary wisdom' (Davies *et al.*, 1998) of citizens, an approach could be made to determining priorities in a politically accountable way that respected the norm of democratic equality. In many respects, the experiments with citizens' juries and so on have been successful. There is better public consultation now on a whole range of public policy issues than there was fifteen years ago. However, experience also shows that such forms of involvement offer little by way of solution to the hard choices that health care allocation often involves. Citizens can show ordinary wisdom, but any form of wisdom in these matters involves an appreciation of how difficult the issues can be and how complex the considerations are that need balancing with one another. The result is that the reported deliberations from public consultation can read like a thoughtful reflection on the problem rather than a purported solution – witness the recent report by the NICE Citizens Council on age and health care.[1]

By the same token, when citizens deliberate they often recognise that because the issues are complex, there can be no substitute for the exercise of professional judgement. So, the argument goes full circle. Responsible health care allocation needs to be more explicit if it is to meet the demands of political accountability. Politically accountable decision-making in a modern democracy requires public consultation, which can be fostered through new forms of public involvement. But these forms of public involvement end up highlighting how complex the allocation decisions can be, and by default hand the problem back to the professionals. This problem of reconciling professional excellence with democratic norms seems to me to be one of the great challenges that now has to be faced. If it is a problem in the context of health care allocation, it is even more of a problem when dealing with the implications of health care technologies.

Technology evaluation: the Nuffield Council on Bioethics

In late 1994 Patrick Nairne, who was then the chairman of the Nuffield Council on Bioethics, asked me if I would chair a Nuffield working party on the ethics of xenotransplantation, or animal to human transplants. The topic seemed

intriguing for a number of reasons. I knew from the work that Bill New had done at the King's Fund that the problem of organ shortages, though one of how fairly to allocate resources, was quite distinct from the problem of how to allocate fairly public expenditure on health care. With public expenditure decisions, one can always argue that resource shortages will be alleviated with economic growth. With human organs, one faces supply constraints that reflect the willingness of citizens to donate and the happenstance of car accident rates and the like. Organ donation is thus a good example of Titmuss's (1970) idea of the 'gift relationship', in which transfers of tangible resources define social relationships. Whatever the faults of the Titmuss approach, it does at least offer an intriguing way of thinking about social policy when we move outside the confines of conventional public expenditure analysis. Xenotransplantation also involves questions about the relationship between human beings and the natural world, and so the topic connected with my interests in environmental issues. Finally, in my mid-forties, I simply could not resist Patrick Nairne's suggestion that the Council had decided that this was a job for 'a younger man'.

Our working party started its task in early 1995 and we produced our report in March 1996. We were spurred on in our efforts when we learnt in September 1995 that the Government had established its own committee of enquiry under Ian Kennedy, and we were determined to be the first to report. We also pipped the US Institute of Medicine to the post as well (competitive emulation can be a great spur to intellectual production). This is not the place to report the detailed findings of our work (Nuffield Council on Bioethics, 1996). All I should say is that we thought in principle that the technology was morally permissible provided certain safeguards were in place, but we also thought that it would be wrong to rush ahead with xenotransplantation without protecting both the welfare of the source animals and that of the general public, which might find itself subject to a new contagious disease from pathogens that had jumped the species boundary.

An interesting feature of Nuffield working parties is the opportunity to work with very clever people in disciplines far removed from one's own. For the first time I saw how offering responsible advice on matters of public policy can involve bringing together evidence and argument from quite distinct modes of enquiry. I also saw how impressive institutionalised science could be in testing over-ambitious and sometimes commercially motivated claims to medical breakthroughs. Yet, though good science is essential, it is not enough. In the first place, it leaves you undecided when it cannot resolve uncertainties as to cause and effect. For example, even if pathogens can in laboratory conditions be made to jump the species barrier, how likely is it that they will in the real world? In such cases, it may not be possible to give reliable estimates that settle the policy question between cautious acceptance and prudent prohibition. And then there

are the value questions to which science cannot give an answer. Suppose you say that using genetically modified pigs as source animals for transplants is permissible and that, for a variety of reasons including their similarity to humans, using chimpanzees is not. What should you say about using baboons as source animals? Rational conversation on the moral status of the baboon soon runs dry in my experience. In short, xenotransplantation is a good instance of a policy question where you find yourself dealing with imponderables and incommensurables. Yet still an answer has to be given.

Here again we run up against the tension between professional excellence and democratic accountability. As part of our enquiry into animal to human transplants, the Nuffield working party undertook a process of public consultation. I remember being struck by the informed and well-reasoned evidence that we received from a variety of sources. In principle, complex policy reasoning is accessible to a wide range of people, particularly in an economy where many people do jobs that involve the range of skills used in policy analysis. On the other hand, in technology appraisal, the relevant science moves very quickly, and requires expertise to appreciate. It is one thing to know that something might be the case. It is quite another to have a sense of whether recent findings mean that it is likely to be the case under a plausible set of conditions. Between 1998 and 2004 I sat as a member of the Nuffield Council, and observed a number of its working parties. I formed the view that there is no substitute in practical reasoning on complex matters to getting a group of really bright and well-informed people together and ask them to deliberate about a complex question of policy, submitting their deliberations to stringent processes of peer review, this last element being essential.

UK policy-making in this respect has, to paraphrase Dean Acheson, lost a tradition and not yet found a paradigm. Until quite recently the dominant style was to rely upon the advice of the 'great and the good' (or 'power elite' depending on your idiom of analysis). That system has come under considerable strain, not least because of BSE. Moreover, there is the 'modernising' imperative towards much more extensive and responsive public consultation. Yet, such consultation can set up a babble of voices, in which the still small voice of reason is drowned. For example, in the recent public debate on genetically modified crops, it has been difficult to get a hearing for the view that such crops may well have an indispensable role to play in alleviating persistent health problems, like blindness and malnutrition, in developing countries, a view that the Nuffield Council has advanced (Nuffield Council on Bioethics, 1999; 2004). The notion of 'deliberative democracy' is fashionable at present, but sometimes the principle of deliberation pulls in the opposite direction to the principle of democracy.

Reflections

I have been fortunate in the acquaintances I have made over the last thirty years, only some of whom I have been able to mention in this account. All have been generous with their time and stimulating in discussion. Unlike other contributors to this volume, I can think of no one who has been a hindrance (but perhaps I never challenged academic and medical power structures as much as some others). With this good fortune, what contribution do I think a political theorist can make to health care research?

I have mentioned more than once that I have always found much of interest and importance in the application of welfare economics to health care. Jack Wiseman, whom I knew at York and with whom I taught for a number of years, once said to me – I think this was intended as an insult – that I thought more like an economist than anyone else he knew. I have come to think in economics that once you know the difference between average cost and marginal cost and are prepared to ask the question of any policy recommendation 'compared to what?', all the rest follows naturally. Why then, apart from an accident of biography, and a lack of facility with graphs, have I not thrown my lot in with the economists? My answer is that the world of policy-making seems to me to be more contestable, more a matter of interpretation, than it is possible to find in the conceptual framework of economics. This is one of the reasons why, though I favour cost-effectiveness analysis, I am always more cautious about cost-benefit analysis. It must always be sensible to ask which of the available options provides a known benefit at least cost – indeed, it would be politically irresponsible to consider otherwise. But how can one value the benefits in a non-contentious way, a way that does not beg the questions that need to be answered? Survey responses among individual beneficiaries show considerable variation, and in any cost-benefit analysis this variation has to be washed away by taking average or median values. A political science analysis, when it is well done, is always open to the possibility that the benefits involved may be framed in new and unexpected ways for both citizens and policy-makers. To take an obvious example, I do not think we understand issues surrounding hospital closures or reorganisations unless we appreciate the symbolic, as well as the service, role of the hospital to the community.

Given the importance of interpretation, and therefore the continued importance of meanings, there is still much to be gained, in my view, from continuing the old discipline of linguistic or conceptual analysis. Linguistic philosophy, as it developed in the mid-twentieth century, could be arid and obscure. However, its practice contained the crucial idea that we should not discuss what we are not prepared to define clearly. Here I think there has been retrogression rather than advance. To give just one example, too many people too often discuss 'equality'

or 'difference', without saying equality or difference in respect of what and for whom. Even a modest training in linguistic analysis would alert people to the fact that equality and difference are relational expressions, and their meaning remains unspecified until we spell out in fuller detail the terms of the relations.

Somewhat more advanced (though not very advanced) logical analysis aids clear thinking and makes for better policy. In *Equality and Social Policy*, I used the logical notion of defeasibility to discuss attributions of equality. Defeasibility is the idea that sometimes a key social term is properly attributed not on the basis of a list of necessary and sufficient conditions, but on the grounds that only defeating conditions would render the attribution invalid. For example, as Hart (1951) pointed out when he introduced the idea, the attribution of contractual relations between persons may be treated as defeasible. Although there are standard conditions for a contract to exist in English law, there is a range of precedents that mean that these conditions are neither necessary nor sufficient. Instead, the attribution of a contract may be defeated or negated by noting the presence of force or fraud, even if other conditions for a valid contract obtain.

Hart's notion of defeasibility was taken up by the Nuffield Council on Bioethics (1995, p. 45) in its discussions of consent to medical procedures, originally under the influence of Onora O'Neill. Rather than talking of 'informed consent', the Nuffield Council prefers to use the notion of 'valid consent', treating this as a defeasible concept where the consent may be invalidated by the presence of force or deception. This approach has considerable importance in the case of tissue samples given for diagnostic reasons and then subsequently used for research purposes. If we insist on conditions of informed consent, the logic is to require the donor of the sample to consent to each and every use of the sample, and in the nature of research this is an impossible requirement. If, however, we speak of valid consent, defeasible by certain conditions, then we allow for the possibility that the donation of the sample implies consent to any use that has ethical integrity. In this way, logical analysis contributes to a climate of politically responsible citizenship – no small feat for the otherwise modest enterprise of informal logic.

How far have I retained the collectivism of my early years? I remain a collectivist with regard to values but an agnostic with respect to institutional arrangements. The core political ideal of the NHS, it seems to me, is that there should be high quality, comprehensive care available to all without financial and other irrelevant barriers to access. The stress on the quality and comprehensiveness of the care marks out this ideal as collectivist, by contrast with a principle of minimally adequate care, which is what would be implied by a purely liberal theory of the state. How best to realise that ideal seems to me to be a complex question, however, and careful experiments with institutional innovation seems to me to be essential, if difficult. I see no merit in the succession of

organisational fixes that successive governments have sought to impose upon the NHS, without any attempts at thinking through their implications or properly evaluating their consequences. If ever there was a case of simple solutions seeking complex problems, this is it. I should like to think that a combination of normative political theory and institutional political science could shed some light on the right way forward in this area, providing some evidence with which intelligent citizens could evaluate the performance of their governments. The task is too big for me, but perhaps others will take it up.

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Notes

1 http://www.nice.org.uk/pdf/Citizenscouncil_report_age.pdf

12

Discovering the QALY,
or how Rachel Rosser changed my life

Alan Williams

Prologue

During the first twenty years of my professional life I was a public finance economist, interested primarily in alternative models of fiscal federalism as they might apply to intergovernmental financial relations in the UK. I wrote a textbook on tax incidence and incentive problems. But I was also interested in how to make cost-benefit analysis work better when appraising different public services, paying special attention to the water industry (becoming a member of the Yorkshire Water Authority and later the National Water Council). My odd conclusion that properly sited reservoirs were potentially more valuable as recreational resources than as sources of water did not go down well.

Later, when health and health care occupied most of my professional life, my activities were so varied that trying to cover them all would have meant that I would have been unable to get to grips with any of them satisfactorily. So I decided to take one strand only, and to follow it through in a coherent manner. This still left me with plenty of options. I could have concentrated on how I helped to develop the sub-discipline of health economics, or how, starting from scratch, York became a world-famous centre for research and training in that field, or how membership of the Royal Commission on the NHS precipitated my mid-life crisis, or the great educational experience I got from the crash course on the perils and problems associated with multi-disciplinary health services research that came with membership of Douglas Black's Chief Scientist's Research Committee. But I decided to ditch all of these and concentrate on the topic with which I have primarily become associated in other people's minds, namely the Quality-Adjusted Life Year (or QALY) as a measure of health.

This particular story starts when I found myself part of Harold Wilson's "white hot technological revolution". Between 1966 and 1968 I was seconded from the University of York to Her Majesty's Treasury, where my official designation was Director of Economic Studies at the Centre for Administrative Studies, the forerunner of the Civil Service College. My principal task was devising and teaching on economics courses for senior civil servants, with the aim of ensuring that they became economically literate (and a few of them even economically numerate). But this was not regarded as a full-time occupation, so I was also designated an "Economic Consultant to the Treasury", and in that capacity became an odd-job man in the Government Economic Service, available on loan to other departments who had little jobs that a part-time economist might usefully do. I have already recounted elsewhere where one of these odd jobs led me (Williams, 1997a), and I am about to recount where another one led me. But first of all I must set the scene by telling you about my brief encounter with Roy Jenkins.

Roy Jenkins had recently been made Home Secretary, and was surprised to

find that the Home Office had no economists amongst its complement of in-house advisers and researchers. So I was drafted in for a few weeks to identify elements in the Home Office's portfolio of responsibilities that might be susceptible to economic analysis. I leave you to imagine the frosty reception that this Treasury spy got as he toured the higher echelons of a very conservative department of state, which was exceedingly (some would say excessively) proud of its achievements, and a jealous guardian of its professional self-esteem. But I soldiered on, ignoring the frequent citation of the catchphrase "Let justice be done though the heavens fall", which was taken to mean that the pursuit of the objectives of the Home Office was not to be constrained by sordid economic considerations, like trying to calculate whether the benefits were worth the costs. Moreover, I was often told that there was very little in their portfolio that could possibly be of any interest to an economist (and this at a time when one of the major issues was immigration policy). At the end of the day I did have to admit that there were a few things that were of little interest to an economist, the most prominent of which was the protection of birds. Everything else seemed to constitute suitable grist for an economist's mill, and especially the cost-effectiveness of the police, prisons and the whole criminal justice system. I so reported, but future progress down that route was severely jeopardised when Roy Jenkins moved on and Jim Callaghan took over. Callaghan's enthusiasm for looking at the cost-effectiveness of the police was distinctly less strong than that of his predecessor.

After my return to York, my interest in the Home Office waned and my interest in the NHS waxed, and I found myself trying to devise a measure of NHS effectiveness that focused on the intrinsic value of health as a good in its own right, rather than merely as something enabling people to contribute better to the welfare of society (especially by maintaining their productivity). This attempt to get away from "human capital" type thinking, which had dominated the economics literature, was partly motivated by the work of one of my former students, Ken Wright, who, as a researcher, was then grappling with the problem of how to evaluate the care of the elderly. When people reach the stage in their lives when they are going to consume more than they produce, then on naïve "human capital" grounds a quick cheap death is the optimal solution. While this was obviously the wrong framework within which to conduct policy analysis in this field, it was not obvious what the right one should be. The solution being explored was to take the widely used measures of Activities of Daily Living (ADL), and use them for evaluative purposes as well as for assessment purposes (Wright, 1974). If enabling people to remain independent as long as possible was the main objective of policy, then assessment of their capacity to perform well on an ADL scale should be a good outcome measure. But how should it be weighted? It could be by the predictive value of each element in

indicating when a person needs to be taken into a care home, but this might not be the right set of weights if what you wanted was how serious each element is in affecting the individual's sense of well-being. For instance, pain may be a far more distressing element for an individual than physical disability, yet it could be the latter that would be used as the indicator that a person can no longer live independently in their own home.

In the middle of all this I remembered that when in the Home Office I had encountered the work of Sellin and Wolfgang (1964), two American criminologists who had created an index of crime seriousness using the views of the general public rather than the views of the police or of the courts. So I got in touch with Vincent Watts, who had been one of the very helpful operational research analysts to whom I had talked quite a lot during my stint at the Home Office, to see if he knew of any further developments of the Sellin and Wolfgang work, especially in a UK setting, that might be adapted for use in health care. My plan was to draw on this and see how best to get the valuations of the general public into the ADL index. He suggested that I should meet his wife, a psychiatrist who had been developing such a measure for use in the evaluation of medical treatments. His wife was Rachel Rosser, and meeting her was the start of a voyage of discovery that has lasted the rest of my life.

The Rosser index

Rachel was interested in measuring "the sanative output of a hospital"; i.e. the extent to which an episode of hospital treatment improved someone's health, and how far this fell short of returning them to full health. It is still the $64,000 question, and for most hospital treatments we still do not know the answer (a matter I shall come back to towards the end). She had constructed a classification system based only on two dimensions, disability and distress. It generated 29 different health states for which she and her husband had sought a set of relative social values to act as weights in a scoring system. Rosser and Watts had started by using Court Awards as their source of social valuations (Rosser and Watts, 1974), but Rachel had gone on to interview a convenience sample of doctors, nurses, patients and members of the general public, which was of more direct interest to me.

Rachel was linked into an international network of health status index developers, so through her I discovered key actors such as Bush in the USA and Torrance in Canada (Berg, 1973). In the UK, some early pioneers were Grogono and Woodgate (1971), but they were not making much impact amongst clinicians, and were totally unknown to social scientists involved in the evaluation of health and social care.

It slowly dawned on me that an important drawback with many of these

indexes was that their measurement scales were rather idiosyncratic, and difficult to interpret. For instance, the Rosser scale used one of the mild states in her classification system as the basic unit of value, and then all other states were rated according to how many times worse they were than that state. This scale had an extreme upper value of 497, a number that had no obvious quantitative interpretation. I knew that we needed to integrate these measures of health-related quality of life with measures of life expectancy if we were to capture the essence of a person's healthiness. When estimating life expectancy the convention is that dead is rated at zero and alive is rated at one. Since what we were doing was essentially saying that some people are more "alive" than others, then we should be working with a scale in which dead = 0 and healthy = 1, and in which states of less than full health would be rated at less than one. These weights could then be used to calculate quality-adjusted life expectancy (i.e healthiness). So I suggested that she rescale her data in that way, a task undertaken by one of her senior researchers, Paul Kind, who was to play a dominant role in later developments when he joined my group at York (Kind *et al.*, 1982).

The main policy interest in the social sciences at that time was not in micro-evaluation but in "social indicators", with a big international programme of work co-ordinated by the OECD, in which the SSRC (which later became the ESRC) was a major player. As part of that work, Tony Culyer, Bob Lavers and I had devised a simple analytical scheme for thinking more clearly about what was involved in generating social indicators of health, as a by-product of which we also devised an analytical scheme for conducting economic appraisals of health care (Culyer *et al.*, 1972). We stressed the inescapable role of preferences in any outcome measure that purports to compare the value of one prognosis with that of another, and the need to make these preferences explicit. Since both length of life and quality of life are valued by people, we used a graphical representation which had length of life on the horizontal axis and quality of life on the vertical axis. And that was the formulation I used many years later in my analysis of the economics of coronary artery bypass grafting (Williams, 1985), of which more anon.

The scene changes

By the mid-1970s I felt that these matters were sufficiently clear in my own head to start trying to convert others to this way of thinking. My basic position, stripped of all qualifications, was that the NHS should be setting priorities in health care by creating a cost per QALY league table, and then, starting with the interventions with the lowest cost per QALY, should work its way through the table until its budget was exhausted. I advocated calculating QALYs using the Rosser Index, since that was simple and it had a UK-based scoring system.

Strangely for an economist, I was less interested in the cost side, though I always stressed its importance as an indicator of the sacrifices that were being imposed on others. In order to enable people to go down my recommended route I got Michael Drummond (formerly a graduate student at York) to produce a couple of resource books to support the more adventurous at a practical level (Drummond, 1981a; b).

In the late 1970s I was presented with many opportunities to pursue this crusade, not all of which proved to be very successful. My most important single convert was Douglas Black, who had become Chief Scientist at the Department of Health. He recognised the potential of this way of thinking, and indeed of the role of health economics in general, in the evaluation of health care. He was one of the people mainly responsible for creating in the UK a cadre of professionally trained health economists unrivalled elsewhere in the world. He invited me to serve on many of his advisory committees, the most challenging being the Research Liaison Group on the Elderly, which took me back to my starting point and Ken Wright's work. I only made a little headway. The same is true of my later membership of the Royal Commission on the NHS, where I found myself totally at loggerheads with the Chairman, Alec Merrison, over the Commission's role. I saw this as doing for the NHS what the Robbins Report had done for Higher Education, but he seemed to see it as some kind of holding operation in which all we had to do was re-state basic principles and hold the line at a general strategic level. After a couple of years the tension got too much for me and I quit, with a strong sense of inadequacy and personal failure.

Then, in the middle of the 1980s, I was invited by Bryan Jennett to make a presentation at a Consensus Development Conference on the role of coronary artery bypass grafting (CABG) in the treatment of angina. This was an opportunity to roll out the cost per QALY approach in all its glory, though with data that was, shall I say, somewhat problematic. But, with help from colleagues in the Department of Health and elsewhere, I did manage to produce some cost per QALY league tables. Much to my surprise, I did not get annihilated by the critics, and my findings proved to be quite influential. I was shocked that no-one had data on many of the key issues, and that they too were filling the gaps by making heroic assumptions. It was a turning point as far as I was concerned, and emboldened me sufficiently to take what proved to be a most important step in broadening my approach to quality of life measurement.

EQ5D and the MVH Group

In comparing the cost-effectiveness of CABG with that of rival contenders for NHS funds, I had once more used the Rosser Index, but I was becoming increasingly aware of the fragility of its valuation base, and the limitations of its

classification system. I wondered whether the time had come for us to have another look at the entire field and see whether, fifteen years later, we could not do better. So in 1987, with Rosser and Kind, I gathered together some interested researchers in Europe to see whether, by pooling our knowledge and expertise, we could identify a "common core" of some three or four key elements that most health status indexes contained, and that were presumably regarded as important in determining whether someone's health was getting better or not. The goal of this "Common Core Group" was to identify an essential minimum data set, not to produce a comprehensive measure containing every item that might be considered relevant by someone or other. Being both multi-national and multi-disciplinary, and having in mind the different purposes to which such a measure might be put, our early discussions were difficult and often tense, but we stuck it out and slowly learned to understand and accept each other's conceptual frameworks and modes of thought and expression. The miracle is that in so doing we did not fight shy of forthright argument, and often made quite severe criticisms of each other's positions, a tradition which persists within the group, now known as the EuroQol Group. From that difficult gestation period emerged the EQ5D descriptive measure of health-related quality of life,[1] which is now widely used worldwide, and is the most commonly used measure in QALY calculations for the National Institute for Clinical Excellence (NICE).

But I am jumping too far ahead. The EQ5D descriptive system is only half the story. The other half is the scoring system, and when used by the NHS I wanted this to be based on the valuations of a representative sample of the UK population. So there began, in 1990, the lengthy negotiations and scientific interchanges with the Research and Development (R&D) arm of the Department of Health, which funded a large research programme carried out under my supervision at York. It led to the creation of the Measurement and Valuation of Health (MVH) Group, the essence of our task being to gather from a large representative sample of the UK population a set of valuations for the 245 health states generated by the EQ5D classification system. We had to adopt a complicated research design to meet the constraints we faced in this ambitious task, and it took us several years to work our way through the intellectual and logistical difficulties involved. But the methodology devised by the MVH Group (Williams, 1995) has been treated as a model replicated by others in their own countries, with gradual modification of detail as we have discovered more streamlined ways of getting to the desired end-product. This was the most important period in my entire life as an empirical researcher, since it required a very high level of commitment to carry it through in the face of a great deal of scepticism and even of outright hostility. I depended very heavily on the support of colleagues, and especially on Paul Kind, who became a key player in a very difficult enterprise. What carried us through was a shared vision about the

importance of what we were doing. Fortunately our R&D support was unswerving, and in 1995 we delivered the goods, namely a scoring system for use with the EQ5D descriptive system, which rested on firmer foundations than anyone had previously achieved in this field, so that we now had an instrument specifically designed for bodies like NICE to use for priority-setting in the NHS.

But at the time there was no body like NICE, and the public health community were, to put it mildly, unenthusiastic about this newcomer on the block, and most clinicians did not want to be associated with health care rationing in any shape or form. So, apart from being picked up by a few enthusiasts, our work languished for years. Rosser herself could not stomach the use of the measure for priority-setting at a population level, still being locked in to a clinical perspective in which evaluating alternative treatments for an individual patient was OK, but choosing between treatments for different patients was unacceptable. In her view, no-one should be denied effective treatments on cost-effectiveness grounds. This is an attitude still shared by many clinicians, despite the fact that they have always sought to be efficient in the allocation of their own time and skills, which, if they considered their own behaviour carefully, they would have to admit was guided by "cost-effectiveness" thinking. But by calling it "clinical priority-setting" instead of "rationing" they manage to avoid the cognitive dissonance that explicitness and honesty would have created. It is still a prominent source of tension between those who take a population perspective and those who take an individual patient perspective when evaluating health care, but every individual clinician is responsible for more than one patient, and has to balance their respective needs and their consideration of what if anything can be or should be done about them. So they all face, and have to resolve, this tension between an individual perspective and a population perspective, whether they realise it or not, and whether they acknowledge it or not.

A QALY is a QALY is a QALY. Or is it?

At this stage I decided that, having delivered the tools, perhaps I could leave others to get on with the job, so in the mid-1990s I turned my attention increasingly to the issue of whether the NHS has objectives other than QALY maximisation, and if so how they might be addressed systematically in the priority-setting process.

Looking back I realised that when developing the methodology of economic appraisal in health care we had perhaps accepted too readily the frame of reference of the clinical trial, where the sole objective is to determine which intervention maximises health. Clinical trials do not look at distributive justice, either regarding the distribution of benefits or the distribution of costs. Indeed, most of them do not collect data about costs at all. I still find it strange that cost

per QALY maximisation is so heavily criticised for ignoring equity, when using the results of clinical trials for NHS decision-making seems exempt from such criticism. Perhaps it is because we provide a frame of reference within which it is easy to pose the question, "what is a healthy life-year worth to different people?"(since that will affect how healthy life-years should be added together). It may seem odd to ask, "what is a reduction in tumour size worth to different people", yet that is an equally important question if you are concerned with equity. Instead, any reduction is regarded as of equal value no matter who gets it, and reductions can be added together, and the means and standard deviations calculated, all quite unproblematically it seems.

In the pursuit of QALY maximisation I took the same stance, namely that a QALY is to be regarded as of equal social value no matter who gets it. Note carefully the terms used. The assertion is not that everyone values a QALY equally, because that is patently false. The assertion is that, from a public policy perspective we *assume* that the value of a QALY is the same no matter who gets it. Anyone is free to challenge that assumption and propose another, and we could then examine the differential consequences for priority setting. But some assumption has to be made and justified. In such a dialogue, a strong ethical case can be made for the "equal social value" position, since it reflects the well-established principle that a doctor should not sit in judgment on the economic, social, moral or personal worth of the person being treated, but seek only to improve their health in a caring but detached manner.

What eventually persuaded me to abandon this position were two apparently disconnected observations: firstly, that public opinion surveys indicated that most people (including the old) thought that the young should have priority over the old when a choice had to be made between them, and, secondly, that the main justification for having a public health care system rather than relying on the private sector was because it would help to reduce inequalities in health.

Paradoxically, it was through the writings of John Harris that I came to see that there was a link between these two observations. John Harris had been one of the strongest ethical objectors to the cost per QALY approach, arguing that the correct ethical position was to accord equal social value to what remained of every individual's life, irrespective of whether it was expected to be long, prosperous and healthy, or nasty, brutish and short. There should no calculation of expected life years, and certainly not of expected *quality-adjusted* life years, since that would imply that someone else could legitimately sit in judgement on the quality of a person's life, whereas Harris's view was that this should only be done by the individuals themselves. This view was held despite the fact that it is other people's money that people are claiming should be spent on them rather than anyone else. In his book, *The Value of Life*, Harris (1985, p. 93) wrote:

"What the fair innings argument needs to do is capture and express in

workable form the truth that while it is always a *misfortune* to die when one wants to go on living, it is not a *tragedy* to die in old age; but it is on the other hand both a tragedy and a misfortune to be cut off prematurely."

This was a challenge I decided to accept, and thinking about the distinction between a misfortune and a tragedy, I saw that the fair innings argument was the missing link between favouring the young and wishing to reduce inequalities in health. The fair innings argument essentially says that each of us is entitled to a certain span of years[2] and those who fail to make it may justifiably feel unfairly treated by life, whilst those who exceed it should consider themselves lucky. But I wanted to go beyond mere years of life and to include such considerations as whether someone's life has been fit and healthy, or disabled and racked with pain, since that too is surely a relevant attribute when considering social justice. So, in 1997, I advocated amending the QALY maximising rule to make it a rule about maximising *equity-weighted* QALYs (Williams, 1997b), where the equity weights would vary inversely with the probability that a person or group would achieve a fair innings. Obviously, the poor as a group would be favoured by this, which was the main purpose of the exercise, but I also observed that men would be favoured compared with women if the same "fair innings" were applied to both, and there were some interesting implications for smokers and non-smokers too. So I started collecting data (mainly from health care professionals) on the sacrifices in total population health that they would be prepared to accept in order to reduce these various inequalities. They show broadly that the median person would make quite significant sacrifices to reduce social class differences in life expectancy, none to reduce differences between smokers and non-smokers, and modest sacrifices to reduce inequalities between men and women (Smith *et al.*, 2004).

But the really controversial implication of all this is that no matter which sub-group you belong to, as you get older your chances of achieving a fair innings improve, so your equity weight goes down. Old people like me have, on any reasonable interpretation of the concept, already enjoyed a fair innings, so my equity-weight would now be less than one. So the obvious logical conclusion from all this is that if you wish to reduce inequalities in people's lifetime experience of health, you have to discriminate against the old. If you won't discriminate against the old, you do not really care about such inequalities. But before considering that matter any further, I must recount what had been going on in another bit of my life.

The rationing agenda

Back in 1995, I had been getting increasingly frustrated by the unwillingness of influential and knowledgeable people to face up publicly to the inevitability of

the "rationing" of health care, and to acknowledge the fact that it had been going on since time immemorial. This reluctance was preventing any discussion taking place with the general public about the principles on which priority setting should be conducted, and comparing them with the principles on which it had historically been conducted, so that we could reach some informed view about how best to proceed in future.

The opposition came from various quarters. The most radical were the romantic idealists who believed that if we only got our act together there would be no such thing as scarcity (Roberts, 1996). Then there were (and still are) those trapped by the emotive connotations of the term "rationing", which to me (having been a wartime schoolboy) was benignly synonymous with distributing scarce resources equitably. Then there were those who did see the need for priority setting, but objected to "mechanistic" solutions (by which I think they meant solutions that are explicit, systematic and evidence-based, and consequently leave little room for those in charge to exercise their own individual discretion). I think a strong argument can be made for publicly accountable decisions to be subjected to such a discipline. Any departure from the rules requires very strong and explicit justification, otherwise priority setting becomes idiosyncratic and capricious. Such departures should not simply be accepted uncritically, or, worse still, welcomed as a militant assertion of clinical freedom. The sole justification for clinical freedom is that it is in the public interest. Whenever and wherever it ceases to be so, it must be (and has been) constrained (Williams, 1988).

Just when I was about to despair of ever finding a constructive way forward, I discovered that Robert Maxwell at the King's Fund and Richard Smith at the *BMJ* shared my frustration, so together we created the Rationing Agenda Group to help fill the void. The members were selected for their known interest in and experience of the priority setting problem, but also so as to minimise the chances that we would rapidly agree on what the actual priorities should be. Indeed, our explicit objective was to identify differences of opinion and get them out in the open, and if some well-known difference of opinion did not emerge within the group, we invited someone from outside the group to express a view opposite to ours. The outcome of this endeavour (which took a couple of years to bring to fruition) was a book containing both our own document ("The Rationing Agenda") and the commissioned think-pieces laying out controversial issues from opposing viewpoints (New, 1997).

One of these controversial issues was my view that in order to reduce inequalities in people's lifetime experience of health, it is necessary to discriminate against the old. Predictably this did not go down well with those crusading for better treatment of the old, the most articulate of whom was John Grimley Evans. The Rationing Agenda Group commissioned a piece from each of us and

placed our opposing views side by side, leaving the reader to form a judgment (New, 1997, pp. 108–123). This same issue arose again more recently when NICE's Citizens' Council considered the role of age in priority setting. Grimley and I were both given an opportunity to convince the Council of the merits of our respective viewpoints (NICE, 2003). I only convinced about one-third of them. But it is an issue that has not yet been resolved, and it is not going to go away. The fair innings argument reverberates strongly with people, and although its link with the inequality-reduction objective is not yet properly understood, when it is people will have to face up to an ethical dilemma they have so far not had to address. No wonder economics is regarded as the dismal science.

What next?

For me the most important future development in QALY measurement is the derivation of equity-weights, as I suggested earlier in connection with the fair innings argument. If we are to move beyond QALY maximisation and embrace also the demands of distributive justice, a QALY going to a deprived person must be given more weight than one going to a less deserving person. This should also help to sharpen up the trade-off issues at present left implicit in policy discussions about inequalities in health within society. But that is likely to take a few years to bring to fruition in a practical way, and in the meantime there are other things that we could usefully get on with in parallel.

I had an opportunity to outline my strategy for doing this when invited, in 2004, to give the Annual Lecture established some years ago by the Office of Health Economics in London. Since that organisation is particularly interested in public policy issues at the interface between the Government and the pharmaceutical industry, I thought a particularly relevant topic would be NICE, so I chose as my subject "What could be Nicer than NICE?" (Williams, 2004). Starting from the observation that NICE currently only applies cost per QALY thinking systematically to its technology appraisals, I suggested that in future all clinical guideline development should also adopt a cost per QALY perspective. Traditionally, clinical guidelines are formulated with the objective of increasing the likelihood that *a patient with a particular condition* will obtain the maximum possible benefit from medical treatment. NICE formally acknowledges the presence of resource constraints, and seeks to work within them in a systematic manner, so its clinical guidelines need to pursue the objective of increasing the likelihood that *all patients* will obtain the maximum possible benefit from medical treatment. Therefore, the recommended treatment for patients with a particular condition must take into account the consequences for other patients' health, and therefore the relative costs. So clinical guidelines need to be designed for cost-effectiveness and not simply for effectiveness. The implication is that

sometimes it will be necessary to deny a patient something a little more effective than the alternative, because the extra costs would be quite disproportionate and inflict too great a health sacrifice on those who are competing for the same resources. When deciding what level of extra costs was acceptable for the NHS, NICE was applying an upper limit of about £30,000 per QALY in its technology appraisal system, which I regarded as far too high, given that UK national income per head was only about £18,000 per year. To be spending far more than this on medical care alone to provide someone with an extra year of healthy life seemed to me excessive, so I suggested that £18,000 be the limit.

My second proposal was designed to counteract the fact that NICE concentrated its scarce analytical and managerial talents on a very small fraction of the NHS's clinical activities. It was obviously impossible for NICE to subject the entire realm of clinical work to such detailed scrutiny, yet it seemed odd to work so thoroughly over innovations whilst leaving the great mass of routine activity unevaluated. So I suggested that each year about thirty clinical interventions, spread across all medical specialties, should be screened for their likely cost-effectiveness. Each specialty would be expected to convene a small expert group to provide evidence about the costs and effectiveness of the selected intervention. To simplify matters at the first stage, on the cost side reference costs could be used. But things look rather more difficult on the effectiveness side, since estimates of QALY gains are needed, which are only rarely possible from existing data sources. Low in scientific status though it is, I suggested using *expert opinion* to fill the gap, and getting a panel of expert clinicians to estimate length and quality of life profiles for patients. By these means a rough cost per QALY ratio could be estimated for each patient subgroup in receipt of the intervention. With luck, most of these would be below my benchmark of £18,000. But those with cost per QALY ratios higher than this would be designated as "on probation", and enter the second stage, during which simple monitoring of costs and outcomes would be required of a large enough representative sample of treated patients in the relevant category to be able to check whether the suspicion that it falls beyond the cost-effectiveness threshold is justified or not. If not, well and good, but if so, we enter a third phase, when negotiation takes place as to whether this treatment is really appropriate for this class of patient, or whether some alternative might be better. If this cannot be resolved, then it is time for this intervention to be referred to NICE for a full-scale evaluation, possibly preceded by the setting up of a proper trial so that it is only permissible to continue treating such patients as part of the trial.

Curiously, by this means we might finally get around to fulfilling Rachel Rosser's original ambition to "measure the sanative output of a hospital". It takes time, patience and hard work to move the system slowly forward, and we have not quite got there yet. Maybe in another ten years?…

Epilogue

So, in my view, the QALY story is only half finished, and I doubt whether I shall live long enough to see the second half played out. I am hoping that, when it is, people will be mildly amused, or perhaps even amazed, about what all the fuss was about. But the most amusing sequel to all of this is that in 2003 the Home Office began to explore ways in which QALY-type thinking, which it saw as being so successful in health care priority-setting, might be adapted for use in the evaluation of the criminal justice system, and I found myself participating in a series of multidisciplinary seminars exploring this possibility. Sellin and Wolfgang please step forward once more. It seems that even in the world of health service research there is a place for poetic irony.

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Notes

1 This has five dimensions (mobility; self-care; usual activities; pain/discomfort; anxiety/depression), each of which can be reported at one of 3 levels (no problems, some problems, severe problems, though the wording differs slightly from dimension to dimension). There is a scale of preference for each of the resulting 243 health states, including some negative values for some very severe states (indicating that being in them is regarded by the majority of the UK population as being worse than dead). For more information about EQ5D and the EuroQol Group in general, go to www.euroqol.org

2 In Psalms it is suggested that this is three-score years and ten.

13

Health policy, management and gardening

Robert Maxwell

This book contains chapters by a varied and distinguished selection of health service policy analysts and researchers, all of them active in the period which has covered my own involvement in health. My position has been different from theirs, in that I can make almost no claim to have been a researcher, and little enough to have been a policy analyst, but I have had a keen interest in health policy and management, and have wanted actions to be shaped by evidence. As a result, I have been much influenced by the work of the other authors, many of whom have also been colleagues and friends. From time to time, I have even commissioned their work.

What I aim to do in this chapter is, first, – in a similar way to the others – describe how I came to be involved, and where this path has led. After that, I will draw on the other chapters to try to discern some patterns from the book as a whole and the period that it describes.

My own intellectual biography

After National Service and Oxford (with a first in English – of questionable value vocationally), I spent a year in the US on a Fulbright Scholarship, doing an MA at Penn and then travelling 30,000 miles in a very old car with a close friend, seeing a lot of North America. The journey challenged many of my assumptions, and reinforced a few prejudices. I was uncertain of what to do next. It was 1958, and I was 24. With somewhat romantic notions of what a career in industry would involve, I began applying for jobs. We were immensely lucky in my generation that jobs were available, and I had a choice. I chose Union Corporation, an international mining firm, with interests mainly in Southern Africa and Mexico, and a Board of Directors in London. In choosing this, I was partly influenced by the fact that my father's father had worked in South Africa, dying there in about 1910. For the next 8 years, I was one of a small group analysing the prospects for a wide variety of types of investment, and monitoring the performance of the group companies. I also found myself, at various times, working on the shop floor of a spring manufacturer in Redditch and a light engineering company in Birmingham (both companies that the Group had acquired), and prospecting for tin in Cornwall. In 1965, I spent some months working in South Africa, because the Board of Union Corporation had decided – for very good reasons – to move to Johannesburg. Exciting as the work prospects were, my wife and I decided that we could not live and bring up our children there at that time, under Apartheid. Not only did we reject the notion of inequality on the basis of colour, we would be bound to act out our rejection, which would have absolutely no influence, because we were not South African. So we returned to England. I could have continued working for Union

Corporation in the UK, but instead decided it was time to move on, to broaden my experience.

McKinsey and Company, a leading American firm of management consultants, had recently opened a London office, and were recruiting in the UK. I joined them in the autumn of 1966, and worked on some productivity studies for BICC, the cablemaker. The then Chairman of BICC was interested in going beyond monitoring the profitability of his companies to assess what – in their different markets – they *should* be able to achieve. In mid-1968, the firm was approached to do its first study in the NHS, at the United Oxford Hospitals. I was at the stage of being judged ready to manage a consulting engagement (rather than simply be a team member), and was asked to take on the Oxford study, which I gladly did. The hospital chairman, Eric Towler, was a self-made multi-millionaire and chairman of Cawoods, a large supplier of oil fuel. He was a man of enormous energy and drive, with surprising sensitivity. He had a passion for high performance in whatever he was involved in, and a deep concern about medical care. His question to us was along the lines "As Chairman of the Oxford Teaching Hospitals, I find the Group constantly short of resources. Is this because it is under-funded, or because it is badly managed?" He recognised, in engaging us, that we had no specialist knowledge of hospitals or health care, but he trusted us to try to understand the complexity of the question, and to give him a straight answer.

Our answer, in due course, was "a bit of both". We were able to show that, compared with other teaching hospital groups outside London, Oxford was indeed under-funded – a finding endorsed, incidentally, by Grimley Evans in his chapter. Its undergraduate teaching hospital status had come late relative to its competitors, and its funding had never caught up. At that time, prior to RAWP, the main determinant of an NHS hospital's budget was some uplift on the previous year's expenditure, so an under-funded hospital tended to stay that way.

Moreover, Eric Towler's commitment to excellence had compounded the problem. For every consultant or other senior vacancy, he wanted the very best candidate and – being the man he was – generally succeeded in appointing him or her. That always incurred budget consequences far beyond the direct salary of the individual appointed. The hospital's services increased in quality, quantity, range, complexity – and cost.

But that was only half our answer. The other half was that the hospitals were in some ways wasteful and badly run. We managed to close one hospital, absorbing the work elsewhere in the group, and demonstrate not only that money could be saved, but how that could be done. We were also critical of the calibre of the group's administration, and of its management arrangements. There was a lack of confidence between the medical and nursing staff on the one hand, and the administrators on the other. We were able to achieve some changes of key

personnel, and design a structure which for the next 10 years made Oxford exceptional in the strength of its partnership between clinicians, management and Board. That, alas, came to an end as a casualty of one of the many subsequent NHS reorganisations that have become a peculiarly British (or English?) 3–5 year curse.

In 1960, I had married into a medical family. Both my parents-in-law were medical, plus one sister-in-law, and another who was a nurse. My wife recalls how I would turn various shades of green during medical conversations at mealtimes. When the Oxford study began, I had family introductions to several of the Oxford surgeons, who thereafter treated me more as a friend than an enemy. I carried three things away from the Oxford work. One was a conviction that better management could make a real contribution to the NHS. Whether at the relatively straightforward level of reducing the waiting time in outpatients, or at the much more complex strategic level, management had a definite contribution to make. Second was a conviction that no medical institution would be well run that did not have the clinical staff fully involved in its leadership. Third, I had never enjoyed any work so much.

For the remainder of my time at McKinseys – which lasted until 1975 – I worked mainly on health studies. In the Republic of Ireland, on a national reorganisation of health services; in New York (in Mayor Lindsay's time) on separating the public hospitals from the city administration; in London, on reorganising the Ministry of Health, and on the 1974 NHS reorganisation; and in the Netherlands on psychiatric hospitals. In a publication called *Healthcare: The Growing Dilemma* (Maxwell, 1974), I tried to draw together some thoughts, based on the available international statistics and my consulting experience, about the issues facing health services in the wealthier countries of the world. The study showed large differences in the level of overall spending on health care, the sources of finance, and the degree of public ownership and control in the twenty countries included. However, many of the trends and issues were common across systems. Compared with the past, and with poorer countries, perinatal, infant and maternal mortality were very low and still falling, and life expectancy was high, and continuing to increase. Population coverage, in terms of access to services, was also high, with the exception of the United States, where a significant minority of the population was not adequately covered by health insurance nor by Government support. Health care spending, in terms of GNP or GDP, had risen persistently from 1950 onwards everywhere where reliable statistics were available, with increasing dependence on Government finance. I predicted that this trend could not continue indefinitely, because of other pressures on resources, but also said that "No attempt to halt the rise in expenditure by cutting budgets without facing up to the effect on standards of care and working conditions is responsible, nor is it likely to be effective".

Fortuitously, it was an interesting time to look at overall patterns, because one important thing was about to change. The oil crises of the mid-1970s were jolting the world economy and making Governments almost everywhere more determined to control further rises in public spending on health care relative to GDP. By the 1980s, there were clear instances of some countries reversing the trend, at least temporarily. However, doing so was never going to be easy because of the human longing for good health, the capacity of science and technology to contribute to medical advance – but seldom to save money – and the personnel-intensive nature of health services. As I had concluded in 1974, the central problem of running health services would continue to be how to use scarce resources to best effect – a task made more difficult by the interplay of public and private funding and provision, and the commitment (in Nye Bevan's words, the mark of a civilised society) that no citizen should be denied good care available to others.[1]

In 1975, when the time came to leave McKinseys, I had no doubt that I wanted to continue to work in the health field. I was lucky enough to go to St. Thomas' Hospital where (with the demise of the Board of Governors) the hospital's large endowment funds were to be controlled by Special Trustees, who needed support both in managing the endowment and in spending the proceeds. For me, the next five years were a very happy time. Sir John Prideaux, Chairman of the Special Trustees and previously Chairman of the Board of Governors, was wise, loveable, totally committed to the hospital and those it served, and a joy to work with. John Wyn Owen, then the District Administrator of St Thomas', was a broad strategic thinker, an effective manager and a good colleague. Working at the local level enabled me to come to know many of the staff as friends, and to appreciate how some of the conceptual dilemmas presented themselves on the ground, and played out in reality. Both John Prideaux and John Wyn Owen supported efforts – in terms of the Special Trustees' objectives – to look beyond the hospital's walls to its broader mission, and in particular the needs of the people of Lambeth, the patterns of health care provision in London, and learning from elsewhere.

Meanwhile, in odd moments, I was also doing a PhD at the LSE under the tutelage of Brian Abel-Smith. I wanted to take further my interest in cross-national comparative studies, and Brian was the doyen in this field. As a supervisor he was all I could wish for: rigorous, patient, encouraging, and economical of time and effort. He was also someone who spanned the worlds of scholarship, policy and action, passionate in the Richard Titmus mould. Out of the thesis came a book, *Health and Wealth* (Maxwell, 1981). My external examiner for the thesis was Rudolf Klein – one of many links with Rudolf, who is one of the great policy analysts of our time.

In 1980, John Wyn Owen decided to leave St Thomas' to take a job with

Allied Medical in the Middle East. From my viewpoint the timing was unfortunate. We had been discussing my taking on an executive role in the NHS, connected with Tooting Bec Hospital – a role later performed with real flair and courage by Ray Rowden. With John leaving, the post of District Administrator was vacant. He and others encouraged me to apply, which I did. But the NHS administrators involved in the appointment process would not tolerate an outsider, partly on the defensible grounds that I had not run a major institution, so I could not be shortlisted. At the same time the King's Fund was seeking a Chief Executive on Geoffrey Phalp's retirement, and that turned out to be me. I was there for the next 17 years, until my own retirement from an executive role, in 1997.

This is not the place to attempt a description of my time at the King's Fund, which coincided almost exactly with the years of Conservative government under Margaret Thatcher and John Major. The worst result of this period in terms of national policy was the increase from twelve to eighteen per cent in the proportion of the UK population living in relative poverty, with a doubling (to twenty-five per cent) in the case of children (Glennester *et al.*, 2004). In relation to the NHS, however, it was – and remains – my belief that the Conservative Governments of this period were committed to trying to make the NHS work better, not to dismantling it. Unfortunately, the NHS was afflicted by repeated reorganisations. Whatever the arguments for organisational change, inflicting it on the NHS, top down, every 3 or 4 years is a recipe for frustration, waste and alienation.

Three ideas that seemed to me powerful and constructive were, first, the recognition of the importance of general management (Griffiths, 1983); second, the conceptual differentiation of commissioning from provision; and, third, the short-lived attempt (under the NHS and Community Care Act of 1990) to create provider NHS Trusts, with greater delegated autonomy. All three, incidentally, are ideas that are still relevant in the context of New Labour's "modernisation" agenda for the NHS. The question is how you apply them. I have no doubt about the applicability of general management, in the sense of a single line of accountability for overall performance, provided that this also recognises that it is operating in the context of intensely personal human needs and of professional skills and judgements. As regards commissioning, it has to be right that the NHS task is to secure people's health and health care, not necessarily to provide all the necessary services itself. Equally, however, that does not necessarily warrant the establishment within the NHS of separate commissioning and provision bureaucracies; nor justify the Private Finance Initiative; nor, in the New Labour context, provide any sound rationale for the requirement that fifteen per cent of contracts must be placed with non-NHS providers, regardless of overall quality, effectiveness and cost.

The task that we were faced with at the King's Fund was how, with modest resources of capital and income, to make a useful contribution to the work of the London hospitals – our historic mission – and those they serve. We saw this within the context of the NHS as a whole, since you simply cannot make sense of London in isolation. Our independence was crucial. As Winston Churchill said of the Church of England, we were not internal pillars of the establishment, more a flying buttress. We needed to work with the NHS, constructively, but not uncritically. Similarly we needed access to Government and the civil service, without becoming their lackeys or their prisoners. We had to get messages across through the media to the public with an independent voice, without so upsetting Government in the process that they ceased to listen.

These balances were not always easy. A few examples of how they worked out in practice are particularly relevant to this book. When I arrived at the Fund, it had two main operating divisions, the King's Fund Centre and the King's Fund College, plus a grant-making department. The College was concerned with management training and development, the Centre with clinical practice and patient welfare (particularly in the context of mental illness and learning disabilities) and the provision of information and library services. In 1982, Sir George Godber published an article in *The Times Health Supplement* advocating the establishment in the UK of something analogous to the Institute of Medicine in the United States. This led me to invite a group of people (including several contributors to this book) to discuss the idea, in July 1983. What we took forward from that meeting was something rather different from what Sir George had in mind. We opted for an institute of health policy analysis, which became the King's Fund Institute, under the leadership of Ken Judge. Besides Ken, its initial staff included Chris Ham, David Hunter, Virginia Beardshaw, Ray Robinson and Sarah Harvey. Over the next twelve years or so, the Institute did outstanding work on a wide range of health policy issues, using evidence rigorously to support its conclusions, and communicating these clearly in its reports and through the media.

Along with the King's Fund's existing institutions, concerned with management development and professional practice, the Institute provided an important, complementary activity in policy analysis and debate. I firmly believe that any independent, charitable Foundation seeking to influence public policy, needs this evidence-based analytic capacity, and that the NHS also needs it. From around 1950 until the Thatcher years, Britain pursued health policies that were, fundamentally, politically non-contentious. Consequently, the Ministry of Health (or Department of Health, as it became) could itself commission and carry out non-partisan policy analysis during this period, and it did. But when health became increasingly contentious politically, as it did from 1979 onwards, Government-commissioned research and policy analysis became increasingly

partisan. The Black Report of 1980 (Black *et al.*, 1980) on health inequalities, provides a glaring example of how research and analysis commissioned by one government was unwelcome to its successor, of a different political persuasion. Without a cross-party consensus, Government is simply not to be trusted for even-handed policy analysis. It is a gap that Foundations can fill – and one that they need to fill, within their particular policy areas. Almost my sole resentment against the regime that succeeded my period at the King's Fund was the dissolution of the Institute and the disposal of its staff. It was, in my view, a piece of wanton vandalism.

More broadly, what I had sought to facilitate at the Fund was a place where talented people committed to a common objective of creating and maintaining sensible, even-handed health policies, and supporting effective, high quality services, would want to work. My favourite management analogy, then and now, is gardening. The gardener does the planting, the encouragement, nurturing and pruning. The plants need air, light, space and freedom. The results owe more to the plants and to nature than they do to the gardener/manager.

Some of the themes on which we worked had started before I joined the Fund and continued throughout my time: nursing development, for example, or changing the patterns of care for people with learning disabilities. Adding new themes was always more tempting than withdrawing others. Among them was support for the Confidential Enquiry into Perio-operative Deaths (CEPOD) in its early days – work which was led by Brendan Devlin and John Lunn, and supported by the Nuffield Provincial Hospitals Trust (as it then was), as well as by the King's Fund. I took a strong personal interest in the definition of health care quality, and in attempts to measure and improve it (Maxwell, 1984; 1992). I also, through WHO, was involved for a number of years in work on the health of deprived urban communities in a wide range of countries, which made me a firm believer in the view that you can achieve nothing lasting without the whole-hearted involvement of the community concerned, and that with pitiably limited resources, there are still things that can be done to make a positive difference to health (Tabibzadeh *et al.*, 1989). Barbara Stocking, at the King's Fund Centre, organised a series of national consensus conferences, held in public, on issues such as open heart surgery and breast cancer treatment, exploring best practice and value for money. With Donald Acheson, Ken Judge and Michaela Benzeva, we pursued the need for actions on health inequalities. Late in my time, in alliance with Richard Smith at the *BMJ*, we set up a working group on rationing, a subject in which several other authors in this book have taken a keen interest: our objective was to map this complex topic and, when there were major differences of opinion – for example on whether rationing should be explicit or implicit, or whether age is a relevant criterion – to have the opposing views heard.

In 1990, we set up a London Commission, chaired by Lord Hussey (as he later became), to examine the health services of London and consider their present and future shape, looking as far ahead as 2010. The Commissioners spanned both the main political parties and covered a wide range of informed opinion. They were supported by Virginia Beardshaw as Secretary, with analytic help from the King's Fund Institute and externally commissioned research. The conclusions, published in 1992 (King's Fund Commission, 1992), were that some fundamental reshaping of London's health services was essential, including a strengthening of primary and community care, some rationalisation of hospitals, and mergers among the main medical research centres to achieve and sustain a critical mass. These conclusions were not universally popular in the London hospitals. They were, however, largely accepted by the Government, whose own Inquiry, under Sir Bernard Tomlinson, reached broadly similar conclusions. Virginia Bottomley, as Secretary of State for Health, staked much on the agenda stemming from these reports, against strong opposition from St. Bartholomew's Hospital (which the Tomlinson Inquiry had recommended for closure), the *Evening Standard*, and others. Mrs Bottomley certainly felt let down by the King's Fund – and by me personally – when I failed to support her on issues around particular institutions, such as Bart's and Guy's. While I agreed with the broad direction of change – and said so – I thought some of the Government's decisions about particular institutions were hasty and unjust. I would have preferred a less centralised process, in which Government would set the policy direction, while allowing each institution to make its own case for change and survival.

In 1995, we called the Commission together again to assess what had happened since the Commission's first report was published. The second report (King's Fund Commission, 1997) was particularly strong on mental health, a topic not adequately covered in the first report. This time, Sir David Goldberg, an expert in this field, joined the Commission, and we also had the benefit of several research reports specifically on mental illness and its treatment in London (King's Fund London Commission, 1998). While these reports were inevitably controversial, I believe that they were timely, and that the directions in which they pointed were correct.

Following my retirement in 1997, I became much less engaged than I was in London and national agendas. I have, however, served as a Non-Executive NHS Trust Director, and since 2002 have chaired the Gloucestershire Partnership NHS Trust, which is responsible for mental health and learning disability services in the county. I also continue to serve (since 1994) as a Trustee of the Joseph Rowntree Foundation, which exposes me to a broader field of social policy research, particularly issues around poverty, neighbourhood renewal, deprivation and handicap.

Some broader reflections

The first thing that struck me in reflecting on the contributions to this book, is their diversity. The writers come from a wide variety of academic disciplines and professional backgrounds, with contributions from various branches of medicine, sociology, economics, and social and public policy and political science. But these are crude and fairly arbitrary classifications. An advantage of the book's focus on the intellectual development of individuals is that the reader can follow the idiosyncratic pathways taken, dictated by chance as well as by personal choice. These are certainly not orthodox, predictable careers. They are highly personal, the patterns only clear with hindsight.

Another difference is where they lie on a spectrum between research at one end and policy analysis at the other. Of course, individuals may shift their position along this spectrum during the course of their life – though more commonly people seem to find their position and then stick to it. So Blane, Bury and Holland are all pretty firmly at the research end of the spectrum. Klein, Coote and Popay, by contrast, are at the policy analysis and development end. Weale, on the other hand, makes his unique contribution by a clarity of rigorous conceptual thinking, tested by confrontation with its relevance and robustness in real life.

What we all share, it seems to me – even those firmly at the research end of the spectrum – is a passionate concern about aspects of health and social justice, and a wish to affect them in practice. We are not concerned with knowledge for its own sake, but for its application. That, of course, does not mean that we necessarily agree with one another. Take, for example, Grimley Evans and Williams on the topic of whether age is a relevant criterion in rationing health care. I will not forget a meeting at which they clashed magnificently on this topic, each passionately convinced that the other is dangerously mistaken.

From the late 1960s onwards, there has been a substantial increase and broadening of health services research in Britain. Mike Bury's chapter describes this from a sociologist's perspective and Walter Holland's from an epidemiologist's. As Walter Holland well describes in his chapter, important foundations for this expansion were laid by the Ministry of Health (as it then was), with Sir George Godber's backing. Dick Cohen, Max Wilson and John Cornish were responsible for developing a network of multidisciplinary units outside the Ministry, and for putting in place the financial and other arrangements to enable them to work. I remember some of this clearly, as, in my McKinsey days, I was involved, with Dick Cohen, in assessing the Ministry's research management arrangements in light of Lord Rothschild's sweeping recommendations about clarifying customer/contractor relationships in all government-sponsored research.

What the Ministry was trying to do was to create the conditions for

multidisciplinary units – each unit with a different focus – of sufficient strength to carry out, for the Ministry and others, a long-term programme of useful, good quality health services research. It was intended that the units would have the freedom to publish their findings – see Walter Holland's interesting story about this issue of principle being raised at an early stage. It was intended that the units would not only train researchers, but would also provide them with career development and security.

Walter Holland also describes the House of Lords Inquiry of the late 1980s, which was scathing in its views on the inadequacy of the Government's support for medical research, and recommended the establishment of a National Health Research Authority. The Chief Scientist of the time was unwise enough to say, in his evidence to the Committee, that "The main aim of DHSS health research is to provide guidance to Ministers...". This was pounced on by the Committee, which opined that "Ministers need a research programme, obviously. The NHS needs a research programme also, and it is likely to be different, both in scale and kind" (House of Lords Select Committee on Science and Technology, 1998). While the Committee was – perhaps intentionally – imprecise as to what the NHS research programme should contain, part of what its members had in mind was certainly health services research with a practical, operational application. While the Government declined to implement the recommendation to set up a new Special Health Authority, it was encouraging to have this all-party support on the record, not only for the continuance of a government-sponsored programme of health services research, but for its substantial expansion.

As I have argued earlier in this chapter, I believe that – particularly at the policy analysis end of the spectrum – there has been a real and threatening change since the mid-1970s in the flavour of work published by the Department of Health itself. From about 1950, for twenty-five years there had been something close to an all-party consensus on health policy in the UK. One sign of this was the non-party tone of health policy documents written by civil servants and published by Government. From the early 1980s onwards – first under Margaret Thatcher and later under Tony Blair – this has changed dramatically. Most of the policy documents – not all – are now written in party political language, with spin. That makes it much more important that independent organisations – such as the King's Fund, the Nuffield Trust and others – speak up loudly and clearly, and tell it how they see it, based on evidence. Of course, we may one day return to a bipartisan national policy on health. Some other countries (e.g. Sweden in the recent past, Canada for a long period in the 1970s and 1980s) sustain a cross-party approach. And – for the present at least – the two main parties are not actually that far apart, at least in England, on the practicalities of running the NHS – though further apart on some more fundamental public policies, such as income distribution. But I would not hold my breath for the

re-emergence in Britain of a sustained period of a bipartisan approach to health.

Another general reflection is that overseas influences on health services research and health policy seem to be much stronger from the US than from continental Europe. In some ways this is understandable, because we share a common language with the Americans and they have a real strength of tradition in health policy analysis. But we ignore continental Europe at our peril. On some fundamentals, American comparisons are too comfortable for us. Yes, we acknowledge their superb clinical standards in many fields, but we rightly criticise them for the exclusion of some forty million people from proper health care coverage, and for their extravagance. As our own expenditure rises closer to that of countries like France, Germany and the Netherlands, we need to face up to the fact that, in terms not only of coverage, but also of standards of service and of clinical medicine, their systems are at least as good as ours, and sometimes better.

Another salutary and uncomfortable thought, having started my NHS involvement in 1968, is that in some ways we have gone backwards since then. I am reminded of a US book about American health policy, published in 1977, entitled *Doing Better and Feeling Worse* (American Academy of Arts and Sciences, 1977). In 1968, most British citizens were profoundly grateful for the NHS. Those who could remember the position before it was set up were absolutely clear that the NHS was an improvement. Those who worked in it were proud of doing so. As a small example, of the outstandingly able consultant medical staff at Oxford in 1968, most had little or no interest in private medicine. What they believed in was the NHS. That would probably not be true now.

Looking ahead, however, that is not necessarily a reason for pessimism. In many ways, the NHS is better now that it was then. Because of medical advances, treatment outcomes are in many cases better. Public expectations have risen, and public tolerance is less. Staff are no less well-trained. We have a Government that is firmly committed to higher funding. What we need is a self-denying ordinance against large-scale organisational change and against centrally-directed micro-management. By all means let the Government set the broad priorities, but it should then encourage people at all levels in the NHS and related services to develop the best care they can, within the resources available. I agree wholeheartedly with Albert Weale's contention that the problem of resource allocation in health care is best thought of on the model of collective insurance by citizens of themselves, rather than the State benignly meeting the need of its subjects. Moreover, in general, the State is not good at running things, and the NHS is probably too big, too complicated and too personal for anyone to run it on a tightly centralised basis. Is a looser, more local, and more locally accountable NHS too much to hope for (not neglecting, in policy terms, the many ways in which health is shaped by other public policies, outside health care narrowly defined)? One of the impressive things about health and health care in the United States

– for all its faults – is the endless local experimentation. There is always something new and different happening. Conceptually, there is no reason why commissioners and providers in the UK should not be just as adventurous in pursuit of national objectives and priorities. Back to my analogy of gardening, we could then encourage desirable change and discourage the undesirable on an incremental basis, rather than digging up all the plants every few years and re-arranging them.

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Notes

1 Foot (1975, p.105), quotes Bevan "Society becomes more wholesome, more serene and spiritually healthier, if it knows that its citizens have at the back of their minds the knowledge that not only themselves, but all their fellows, have access when ill, to the best that medical care can provide".