

schemes aiming at more democratic and socially-based patient involvement. The editors claim that three main ideas link these initiatives. These are: 1) 'holism', which 'attempts to locate all questions about health and ill-health in the wider contexts of lifestyle, culture, and political debate' (page 3); 2) 'equality', which also incorporates acknowledging and representing social differences; and 3) 'autonomy', which involves enabling people to have greater control over their lives in terms of health generally as well as medical regimens.

All of this is entirely laudable and, to a certain extent, the initiatives described do represent some much needed steps to put a broader, structurally-based concept of health back on political and medical agendas. However, as the editors themselves acknowledge, many practical and moral dilemmas remain. Not the least of these is the fundamental question of power: who decides what is health? Arguably, some of the population-based projects, although aiming to listen to people's needs, still end up imposing their own biomedical definitions of health; and the patient-based schemes still have to operate within biomedically determined parameters. Is this 'change' or merely the superimposition of social awareness onto the existing system? Moreover, can such initiatives ever hope to facilitate real change whilst power structures remain wedded to individually-based concepts of health to the neglect of social factors? There is also a practical problem with traditional methods of evaluating the success of these new approaches. The more participatory and dynamic the initiative, the more process and outcome are inevitably intertwined. Who, for example, defines what is a successful or desired outcome once the parameters of health are moved away from biomedical determinants towards those concerned as much with life enhancement?

This book provides good examples of practical initiatives in medicine and in health which should encourage and inspire those working in the field. However, given prevailing power structures, it raises more questions than it answers about possibilities of real change. Ideas may not be enough!

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Personal Data Protection in Health and Social Services

P Pearce, P Parsloe, H Francis, A Macara and D Watson, 134 pages, London and Sydney, £19.95 hardback, £8.95 paperback, Croom Helm, 1988

Information is a key resource in the provision of health and social services. It is also a resource whose character and availability has been transformed by technology in the last two decades. The extensive introduction of computers has expanded the capacity for bureaucracies to collect, store, manipulate and retrieve information. And because information is closely connected to deeply held sensitivities about privacy, secrecy and integrity, there has been growing pressure to regulate the use of information. One of the most notable results has been the 1984 Data Protection Act. This piece of legislation is intended to establish control over the use of automated information and to allow people ('data subjects', in the jargon of the Act) to have access to that information.

The simple outlines of the Act, however, cover a multitude of issues. Clients of agencies and bureaucracies are not the only people with an interest in the information. Medical confidentiality, for example, is not something that can be observed in all cases (for example, notifiable diseases); equally access has to be constrained where information about one person refers to another. *Personal Data Protection in Health and Social Services* studies these issues in the context of the new legislation (although the book seems to have been written before the Act was fully implemented).

The authors, with backgrounds in law, social administration, medicine and the social services, are agreed that the use of technology does not in itself transform the arguments about the ethics of data collection and use. On the other hand, given the immense capacity and speed of computers, the question as to what information ought to be collected, in what form and for what purpose has to be answered with a new urgency.

Penelope Pearce sets the background with an elegantly lucid survey of the current state of English law on 'information' and the changes made by the Data Protection Act. Neither the new nor the old law gives a general right to information. The 1984 Act merely

grants 'a right of subject access'. But even this modest intention, argues Pearce, is not easily implemented. The Act makes it difficult for data subjects to assert their legal rights. They have to know where to look, to know who is collecting what under which heading. And if the local authority is registered as a single user, rather than as a group of discrete agencies with separate registration, then it is able to transfer information from agency to agency without the citizen's consent.

At the same time, the Act can actually inhibit disclosure where it might be beneficial. This is the result of a desire to protect the source of information and the privacy of third parties. If these others can be identified in the record, then it cannot be disclosed. In theory this could prevent access to almost all medical records since the source is bound to be known to the patient. Another constraint on disclosure is the requirement that the data not be harmful to the subject. But there are obvious difficulties here: how is harm to be judged? and how can redress be sought without the 'harmful' data being known about? A final problem posed by the Act is the absence of guidance as to whether parents have the right to information about their children.

All these topics reappear in the subsequent chapters, which analyse the practical application of data protection and access. Phyllida Parsloe devotes her discussion of the social services to establishing an appropriate code of conduct for data use. The social services tend to operate a *de facto* open access system, but for it to work properly there have to be principles to guide the collection and recording of information. Parsloe emphasises the need for a clear sense of the *purpose* for which information is collected. Equally, third party protection has to operate in information relating, say, to child abuse. If sources cannot be protected, they will not participate.

A striking difference emerges in the practices of social and medical services. Where the former favour openness, the latter work within assumptions of confidentiality. Parsloe argues that this is justified by the different client-professional relation involved in each case. The argument is not fully developed, but it deserves further exploration.

The particular case of medical information is addressed by Huw Francis and Alexander Macara. They argue that the doctor-patient relationship depends on trust, expressed in confidentiality, but that

successful treatment requires the doctor to use the information publicly to organise the necessary resources. On the matter of patient access to records, Macara and Francis steer a middle course between unrestricted access and absolute secrecy, and argue for 'modified access'. Under this, patients should be allowed to see their records, unless the health professional bars access on the grounds that the disclosure threatens harm to the patient or poses third party problems. If the patient is unsatisfied she or he can request some kind of second opinion. Such a proposal found no favour either with the BMA or the Government, despite the fact that the position of both seems to conflict with the spirit of the Act.

A final chapter by David Watson seeks to draw attention to the ethical issues which underlie the previous, more practical discussions. Rights to information, he contends, must be grounded upon a clearly established concept of privacy and the rights attached to it. He succeeds in raising some important questions about the value placed on confidentiality and privacy, linking them to an individualist ethic. As the questions proliferate, though, the arguments get rather lost, and the chapter might have benefited from a more focused approach.

The same might be said of the book as a whole. There are some unnecessary repetitions (especially since this is a short book). More seriously, the volume lacks both an introduction and conclusion, and the reader is left without any clear sense of direction. This is a pity because the book addresses an important topic, and begs some crucial questions about the way in which professional ethics need to be defined in relation to the collection and transmission of information.

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Measuring Health: a Practical Approach

Edited by George Teeling-Smith,
268 pages, Great Britain, £26.50, John Wiley and Sons, 1988

With the demand for health care apparently infinite and its supply finite,

harsh choices are inevitable. With demand increasing due to demographic pressures and rapid technological advance, especially in molecular biology, decision-makers in the health care system, be they politicians, managers or clinicians, are having to deprive patients of care from which they could benefit in terms of enhancements in their length and quality of life.

What criteria should these decision-makers use when making such life-and-death decisions in a world in which most health care therapies have not been evaluated thoroughly and where there is little agreement about how to measure health? The authors of the chapters of this book seek to clear the jungle around the base camp of this long climb up the Eiger!

After an editorial introduction, Sonja Hunt discusses the merits of one health measure, the Nottingham Health Profile (NHP). Paul Kind in chapter 3 reviews the strength and weaknesses of the NHP and other measures of the quality of life which have been developed in North America and the UK. Gillian Capewell offers another review of this difficult area in chapter 4 and then Martin Buxton and Joy Ashby report some results of using the time-trade-off method. Further examples of applications of these measures are presented in a series of chapters on Parkinson's Disease (Welburn and Walker), cancer (Schepper and Clinch), rheumatoid arthritis (Patterson), heart disease (O'Brien) and irritable bowel syndrome (Stevens, Poston and Walker). The authors of final chapters examine applications in management (Williams) and clinical practice (Roberts).

Because of finite health care resources, competing health care activities, preventive, diagnostic and treatment, have to be prioritised. How do the attempts to measure health which are reported in this book facilitate prioritisation?

There are clearly many ways in which the quality of life can be measured. 'Guesstimates' of the effects of competing therapies on the quality of life (QoL) can be combined with poor data on post operative/treatment survival to construct estimates of quality adjusted life years (QALYs). Both the ingredients, estimates of the QoL and survival, are crude. However, they do produce an explicit judgement and the challenge is how to improve the accuracy of this judgement.

This book shows quite clearly there is no 'gold standard' for measuring health. However, the work reported here

demonstrates that progress is being made and that guidance for decision-makers can be produced by careful and patient application of measurement instruments which are gradually being tested and improved.

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Human Genetic Information: Science, Law and Ethics

Ciba Foundation Symposium, x+212 pages, Chichester, £35.95, John Wiley and Sons, 1990

The 40th anniversary of the Ciba Foundation was marked by celebrations in June 1989 which included this symposium. Twelve papers, plus an introduction and summing-up from Sir Gustav Nossal, the chairperson, cover recent developments in human genetics from a variety of perspectives – scientific, legal, religious and philosophical. The discussion following each paper is reproduced, and contains some of the most valuable points in what is a very worthwhile volume. Various ethical positions are discussed, including the relative merits of the language of interests and the language of rights (pages 105–106).

The issues fall into four categories: the first three concern the acquisition of human genetic information, the communication of this information, and its applications. The fourth concerns the wider religious and philosophical significance of human genetics.

In the first category, the possibility that some research could lead to 'dangerous knowledge' and should therefore be prohibited is rejected (page 75). Whether it is *worthwhile* to attempt to sequence the entire human genome, however, is considered by Sydney Brenner. He argues that since 98 per cent of the human genome is 'junk', the important 2 per cent should be sequenced first. In the ensuing discussion he agrees that the primary justification for the work is medical benefit.

Turning to communication, there is concern that 'the public' is viewed as an uninformed body to whom the scientific