

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



## Measuring Health: a Practical Approach

Alan Maynard

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