Reforming Healthcare by Consent: Involving Those who Matter

Edited by Tom Ling, Abingdon, Radcliffe Medical Press, 1999, 235 pages, £22.50.

This book is a collection of essays reflecting on the influence and engagement of users in health care development. The word collection feels appropriate here as the essays are very disparate, and without connection, cross-referencing or thematic. There are very short chapters (a delightful one by Roy Lilley is only three pages long) but others are many pages long with few subheadings, diagrams or pictures to relieve the reader. (I have to admit like Alice to not enjoying books that “have no pictures or conversation.”)

Such is the speed of change in the National Health Service (NHS) that any publication will inevitably be out of date by the time it is published. The introduction acknowledges that the creation of the book has taken a number of years. This is very evident. Some chapters were written after the changes to the NHS were announced in December 1997, but others seem to have been written long before that. We are embarking on a radical change to the NHS and the message from the book is that health care consumers must influence the shape of services. Although the book was published in 1999 and therefore the demise of general practitioner (GP) fundholding was only weeks away, the mention in the first chapter both of fundholding and family health services authorities (which were written out of the NHS several years ago), and only a passing reference to primary care groups in the rest of the book, detracts from that message.

This book does not fully make the case for the ethical imperative of consumer involvement in every corner of health care policy and practice. Many areas are tackled but there are gaps. There is a large endeavour to involve consumers in the whole research agenda, still in its infancy, but this is not mentioned. Nor is the importance of involving consumers in quality (nowhere are the words “clinical governance” mentioned). The tumultuous fallout of the General Medical Council (GMC) hearing of the Bristol doctors is touched on presciently by a couple of authors. But the implications for the relationship between professional and user is not addressed, and there is no mention of the Bristol hearing or its repercussions. It would have also been valuable to have had an international perspective on what is a global issue.

Having said that, there are some wonderful chapters that absorb, challenge and inform. I found the chapters on the role of the pharmaceutical industry and its relationship to the public, Let the industry talk to patients, and the chapter on the lack of consumer involvement in information technology (IT), particularly thought-provoking. But with the rather unsystematic approach to a diverse range of issues, you will have to dig deep for gems.

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The Birth of Bioethics


What is bioethics? Is it a discipline in its own right or a sub-field of other disciplines such as philosophy, law or theology applied to moral problems in health care? Perhaps the best way to approach this question is to see it as an academic discipline which represents a way of doing ethics somewhere between the logic of moral philosophy and the exigencies of practical policy. Albert Jonsen has written what appears to be the first broad history of bioethics, covering its origins and evolution between 1947 and 1987. According to Jonsen it emerged as a distinct discipline during the 1960s, when various scholars migrated from academic subjects such as law, philosophy and theology, and developed new ways of viewing the traditional ethics associated with medicine. At present bioethics has three professional associations with over 1,000 members and almost 200 centres. Jonsen notes that over 3,500 books and articles on bioethics have been listed. Bioethicists are in great demand by governments and the media, and bioethics commissions and conferences are to be found throughout the world.

In this detailed and widely researched history Jonsen portrays the driving force behind the development of bioethics as the steady accumulation of public concern with the ambiguities generated by scientific develop-
mments in medicine, where the simplified image of the caring country doctor with his black bag was replaced with images of medical teams employing modern scientific resources in intensive care units and transplant centres. Moral issues concerning benefit and harm, which were once considered obvious and non-controversial, became challenging when viewed against a social background wherein greater emphasis was placed upon respect for the individual as a decision maker. Thus questions about justice and the meaning of life and death, long debated by lawyers, philosophers and theologians, took on a practical aspect within the context of new scientific medicine.

Jonsen examines the issues which generated most concern in the post-war years, such as human experimentation, genetic engineering, termination of life-sustaining treatment, and problems related to the new reproductive technologies. These topics occupy the five central chapters of the book, where each one is situated in its historic context and its treatment in bioethical discourse is examined. It is worth noting that these historical studies are not confined to the forty years of bioethics which is the intended scope of the book. Jonsen recognises that many of the philosophical and theological problems have a long ancestry and his excursions into their historical origins will be appreciated by the contemporary reader. There is also a wealth of information concerning the early conferences and commissions dealing with bioethical issues, together with the arguments of some of the major figures in bioethics. As a prominent member of the US President's Commission Jonsen is particularly informative with regard to the debates which resulted in several of its influential reports.

Many of Jonsen's historical and ethical surveys testify to the immorality of the unrestrained application of science to medicine throughout this century, from abuses in research on human subjects to the infamous pursuit of eugenics, the early years of organ transplantation, attitudes towards the dying and the dead, and the controversies generated by scientific involvement in human reproduction. The emergence of bioethics is consequently an expression of public concern.

Towards the end of the book there is a chapter which examines bioethics as an academic discipline and the search for a general theory for bioethics; a chapter on bioethics as a form of public discourse which is carried out by many people outside of the academy, and a final chapter which locates the origin and evolution of bioethics in the American liberal tradition. By "liberal tradition" Jonsen means the ethos in which the US civil rights movement emerged and the opposition to American involvement in the war in South East Asia, which gave expression to concern for the rights of individuals and a distrust of authority. This would suggest that bioethics is primarily an American phenomenon, and whilst the emergence of bioethics outside the US is covered briefly, that is a subject which lies beyond the scope of this book.

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Rationing: Talk and Action in Health Care


Rationing, a word destined to bring shivers down the spines of our political masters, despite the general agreement of all who work within the National Health Service (NHS) and the vast majority of the public that, however one may choose to label it, the central issue is about how choices are to be made under conditions of scarce resources. The many authors come from within the service or from policy institutes, and include clinicians, economists and analysts. Professional philosophers are less well represented. There is little to be found in the way of underpinning assertions based on ethical theory, and where attempts are made, the results are not altogether successful.

The articles cover the entire range of issues that have attracted the interest of those working in the field. I particularly enjoyed the debate between Alan Williams and John Grimley Evans on age as a criterion for rationing, and between Tony Culver and John Harris on the objectives of the NHS. By far the most original article, I thought, was that by Len Doyal and Joanna Coast, who discuss the extent to which rationing should be made explicit at the different levels of decision making. It is so much a part of the culture of the NHS that decision making should be explicit, that the counterargument to suggest that explicitness might have a disutility of its own or that it might not best serve the interests and welfare of individual patients was to me quite refreshing. Many clinicians have intuitively always believed this and have not been persuaded by the arguments for explicitness and public participation. They will find some comfort in the more formal articulation of their views, not only by Coast, an economist, but by commentators such as David Mechanic, a sociologist, and David Hunter, a policy analyst, in the referenced literature.

The second section of the book, which debates the issues described above, was the most successful and enjoyable. The first section, said to deal with "the theoretical policy debate", was less successful and in my view did not achieve its stated aim. Nevertheless there is much common sense and realism to be found in Bill New's chapter, written on behalf of the Rationing Agenda (RAG), and in Chris Heginbotham's robust counter to the arguments of the idiosyncratic Anti-Rationing Group, in his chapter on the inevitability of rationing in the NHS. I was disappointed to learn that a consensus from the RAG, that the method of financing the NHS should be based on general taxation, had emerged without any discussion as to the reasons for that consensus, by without an ethical dissection of the benefits and risks of a mixed economy in the funding of health services. The central importance of equity or fairness as a guiding value in the delivery of health services can be accepted by most if not everyone, but there has been little debate as to whether an managed introduction of a privately funded mix will lead to greater or lesser degrees of equity in a social environment where greater accessibility to health information and consumerism predominate, and where technical and scientific developments are likely to escalate even further the costs of health care.

In the third section useful summaries are given of practical attempts to apply rationing in real clinical situations. Experiences from other countries are always informative, and the information from both Sweden and New Zealand proves to be no exception. The attempt by David Ebbs and his colleagues to provide a framework for rationing in a general practice setting is a brave attempt, but I am not persuaded that there are no significant