Gene Technology and Social Acceptance


Over the past 15 years, since the publication of Walter Bodmer's report for the Royal Society, the public understanding of science (PUS) has become a positive industry in the UK. Initi- 
ally intended by the natural scientists to fos- ter public acceptance of science, it has gradu- ally drawn on a longer and deeper academic tradition in Britain of the social studies of science. Some of that social science research pre- 
dicted the recent “moral panic” over genetically modified (GM) crops and food, but both natural scientists and governments have held social science in low esteem for many years, so it went unremarked at the time.

The hypothesis of those who launched PUS was that the public was merely deficient in factual knowledge and that public acceptance of science could be improved simply by setting out “the facts.” Social studies of science had drawn its strength from the vacuity of this “deicit model”, both theoretically and empirically, long before the GM furor provided an experimental falsiﬁcation of the hypothesis that falsiﬁcation III. With the publication of a seminal House of Lords report on science and society in 2000, a more socially informed way of thinking is now entering the British mainstream.

This book offers a view from a rather differ- ent perspective: it is neither British nor a work of social scientists, but comes from the head of corporate communications for Novartis (who also acts as professor of health policy at a Swiss graduate school) and from the commu- nications manager of a major German chemi- cal company. As one might expect from a con- tinental European perspective, there is a lively awareness of social factors in the acceptance of new technology, but sadly the conceptual framework within which these authors work appears dated and unrealistic.

It is an abuse of language (and of the con- ceptual clarity that should underlie the use of language) to divide, as these authors do, pub- lic reaction to GM technology into “rational” and “emotional” categories. Although the authors try to limit the damage by noting that the emotional factors are not “any less valid, less legitimate, or less important”, it follows immediately that the “emotional” factors are irrational. Nor does it help that their subheadings under “rational factors” include: medical beneﬁts; economic beneﬁts; environmental beneﬁts; and social beneﬁts [my emphasis]; whereas the “emotional factors” include: concern about safety and aversion to risk. This is not classiﬁcation but rhetoric.

In premodern (peasant) societies, almost all risks are natural disasters, Acts of God, such as crop failure; famine; ﬂooding; pesti- lence, and devastating weather. In contrast, in a modern society risks almost all result from social choices of technology—whether: to build a nuclear power plant or to burn coal; to slaughter a nation’s cattle herds or hope that BSE will not transmit to humans, to plant GM crops. Although we accept socially imposed technological risks—indeed it would be im- possible to function in society if we did not—that acceptance is provisional and will turn to rejection if anything goes wrong. The character of risk changes from premodern to modern society; one does not sue God for a natural disaster, but we believe it justiﬁable to sue if a train crashes, or an aeroplane falls from the sky. Socially imposed technological risks are a central, deﬁning element of life in modern society, not a secondary “emotional” factor. Strange that, although the fundamental text that sets out this thesis on risk—The Risk Society—was originally published in German by a German sociologist, Ulrich Beck, it appears in this book to be an essay written in the UK by Anthony Giddens, now director of the London School of Eco- nomics, but he appears not to be cited either. Despite its flaws, there is a great deal in this book. It attempts a “big picture” overview, and much of its factual and historical content is interesting and valuable. The authors provide a clear exposition of the technical aspects of biotechnology itself and do appreciate many of the social and ethical issues that it raises. It seems to represent a genuine attempt to reach out from the laager of technological suprema- cists to the wider community to seek consul- tation and consensus. As such it is to be wel- come, for no purpose is to be served by repeating, with genetic modiﬁcation, the mis- takes of nuclear power. But for all that, this book also shows just how far there is for the scientiﬁc-industrial community still to go before it fully appreciates the rational founda- tions for the public to assert its voice, its values, and its expertise, as well as, and against, the well-articulated voice, values, and expertise of the biotechnology companies.

M O’Dowd

Medical Ethics: Sources of Catholic Teaching


This third edition of O’Rourke and Boyle’s Medical Ethics: Sources of Catholic Teaching is a useful and comprehensive collection of state- ments published for the most part, by the central authorities of the Roman Catholic Church, the National Conference of Catholic Bishops in the United States and the bishops’ conferences of individual US states on a wide range of issues in the area of medical ethics. The statements are arranged alphabetically according to subject matter. It is useful to have such a wide range of documents available in one volume, many of which would otherwise be accessible only with diﬃcuity. The docu- ments included range from major encyclical letters issued by more recent popes on matters such as human sexuality (Humanae Vitae by Paul VI) and human life (Evangelium Vitae by John Paul II) to ad hoc responses by individual bishops to very particular ques- tions with which they have been faced, and upon which they have felt the need to offer some guidance. Unfortunately no guidance is provided as to the weight and authority that is to be given to the various documents. For example, a major philosophical and theologi- cal treatise such as the encyclical letter, Evangeli- um Vitae, by John Paul II is presented alongside an ad hoc response from the bishops’ conference of an individual state to a particular question that has arisen, as though they were of equal signiﬁcance and import- ance. This detracts seriously from the useful- ness of the collection and gives a misleading weight and authority to a great many of the statements gathered together here.

The impression could also be that documents such as these provide the only, or indeed the major, source for Catholic ethical understanding, and in the area of medical ethics, whereas of far greater signiﬁcance and abiding value are the contributions to this ﬁeld of medical ethics of authors such as the late Richard McCormick, John Paris, and Albert Jonsen, to name but a few of the more prominent.

T Willie

The Ethics of Clinical Research in Developing Countries


The discussion paper produced and published by the Nuffield Council on Bioethics about the ethics of clinical research in developing coun- tries is a timely, useful and (for such a concise publication) comprehensive document. It will prove useful for those planning research in developing countries, as well as for those already working in the developing world and planning research. The sponsors of research should also read the paper, whether they are pharmaceutical companies or a host country’s statutory bodies, reviewing research proposals.

The topic has most recently been discussed in the context of the controversy surrounding trials of zidovudine (AZT), but the authors rightly point to a much wider agenda. They also convincingly highlight the diﬀerences and diﬃculties that are particular to research by developed countries in developing countries (rather than those inherent in all research). They also touch, however, on the issue of self-generated research in the developing world.

Perhaps the general issue can most easily be summarised in terms of the competing argu- ments for universality in the ethics covering research (which can become unhelpful or paternalism from the developed world), and for acknowledging the need for local self determination (which can be seen as condoning unethical behaviour). Taken to the ex- treme the “Universal School” may result in no potentially useful research being done in the developed world because of the fear of any harm. The local self determination group can, however, fall into the dangers inherent in having varying standards and therefore lead...
to the developing world being exploited by the richer and more powerful North.

More broadly, it is possible to see this branch of ethics as a subset of the overall ethics associated with development, under-development and poverty. Many of the special dilemmas of health care and poverty are common to all developing countries. As a result, the guidelines issued by the Joint United Nations Programme on HIV/AIDS (UNAIDS) perhaps clarify the issue, but are unapplied because of a lack of clear and absolute guidelines. This may enable a compromise to be reached among the various processes of care. Starting with a description of Waale’s theory of responsibility or responsive government, he presents numerous arguments with examples of implicit and explicit rationing, public involvement in, and political and medical accountability for, rationing decisions, pointing out the potential conflicts between different moral concerns or levels. Clinicians have a primary obligation to treat the individual patients before them, managers to see that public resources are not wasted, and politicians to use the resources fairly and to balance interests and expectations of different sections of society. Within a given budget constraint, are government and health authorities making decisions based on the broad remit of health care rationing and health outcomes. As Butler states, outcomes are elusive things. Moreover, improvements in health are likely to reflect a variety of social, economic, environmental, educational, and occupational changes among which delivery of care is only one. In situations where all objectives cannot be achieved and comparisons between different outcomes have to be made, how can we fairly establish that some objectives are morally to be preferred to others? Should outcomes be perceived in terms of meeting individual need, the maximisation of total health gain (utilitarianism for example), using quality adjusted life years (QALY) or as the narrowing of the health gap between rich and poor?

Chapter 5 addresses the ethical issues of health care rationing and health outcomes. As Butler states, outcomes are elusive things. Even at the patient level measuring improvements in health may be tricky, but at population level, where ethical questions are more likely to be posed, the difficulties multiply. Moreover, improvements in health are likely to reflect a variety of social, economic, environmental, educational, and occupational changes among which delivery of care is only one. In situations where all objectives cannot be achieved and comparisons between different outcomes have to be made, how can we fairly establish that some objectives are morally to be preferred to others? Should outcomes be perceived in terms of meeting individual need, the maximisation of total health gain (utilitarianism for example), using quality adjusted life years (QALY) or as the narrowing of the health gap between rich and poor?

Chapter 6 singles out this book from others on the topic. This chapter contains a series of stories that the author has gathered from professionals who deliver health care. In order to present an unbiased selection of stories, Butler’s includes anecdotes from doctors, clinicians, nurses, and managers. Despite their different contexts and locations contain a common thread in that although none say so openly, each clearly describes a decision which implies rationing. These stories clearly bring out the conflict between moral concerns at the different levels.

From a professional point of view this book is comprehensive, thought-provoking, readable, and highly recommended.

M Longo

The Ethics of Health Care Rationing: Principles and Practices


This book is about scarcity and rationing in health care and the ethical questions they raise. It is based on the premise that if the aim of a responsible government is to balance the nation’s varied claims upon the collective purse, then no government can be morally blamed for failing to remove the need of rationing from the National Health Service (NHS), and thus rationing as such cannot be considered as a moral concern or level. The question that needs to be addressed therefore is not whether rationing itself is unethical, or even whether any particular distribution mechanisms are unethical, but whether they are structured and work in morally acceptable ways, and lead to morally acceptable results. In the first chapter Butler describes the gap between needs and resources. He describes what has been done (mainly) in the UK as a way of providing the background to the rationing debate. The second chapter addresses the moral basis of rationing by focusing on the ethical assumptions on which personal qualities we are prepared to accept as a fair basis for discriminating between individual patients. The author could not have chosen a simpler and yet more effective example to drive us through the debate.

Chapters 3 to 5 tackle the debate on rationing from a different point of view. Here Butler explores the moral issues of fairness and justice through the structures, processes, and outcomes of health care. Given that health services will always be in short supply in relation to potential demand, he asks whether they are structured and organised in ways that will promote people’s fair and equitable access to health care. This question is addressed by taking the reader through three competing theories of justice: those of Rawls (social justice), Daniels (fair equality and opportunity), and Doyal (human need). All three share a common feature in highlighting that the structure and functioning of health care cannot be left to chance or interest but must be planned and implemented in ways that make explicit the principle of justice they are seeking to achieve.

Butler then takes the reader through the various processes of health care. Starting with a description of Waale’s theory of responsibility or responsive government, he presents numerous arguments with examples of implicit and explicit rationing, public involvement in, and political and professional accountability for, rationing decisions, pointing out the potential conflicts between different moral concerns or levels. Clinicians have a primary obligation to treat the individual patients before them, managers to see that public resources are not wasted, and politicians to use the resources fairly and to balance interests and expectations of different sections of society. Within a given budget constraint, are government and health authorities making decisions based on the broad remit of health care rationing and health outcomes. As Butler states, outcomes are elusive things. Moreover, improvements in health are likely to reflect a variety of social, economic, environmental, educational, and occupational changes among which delivery of care is only one. In situations where all objectives cannot be achieved and comparisons between different outcomes have to be made, how can we fairly establish that some objectives are morally to be preferred to others? Should outcomes be perceived in terms of meeting individual need, the maximisation of total health gain (utilitarianism for example), using quality adjusted life years (QALY) or as the narrowing of the health gap between rich and poor?

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From a professional point of view this book is comprehensive, thought-provoking, readable, and highly recommended.

M Longo

Speaking for the Dead: Cadavers in Biology and Medicine


This book is well-timed. Jones has produced a broad-ranging work focused on a novel subject: the cadaver. In this year alone, high-profile media issues have included the non-consensual storage of postmortem examination tissues at Alder Hey; the trial of Dr Heinrich Gross, for killing and storing the brains of children in Austria in the second world war; debate about the medical uses of fetal tissues, and the postal sequestration of indigenous remains from museums. Speaking for the Dead is underpinned by a profound respect for cadavers. Jones makes the claim that respect accorded to persons (and their wishes) extends to their tissue after death. He bases this on both utilitarian and Kantian grounds. Hypothetical arguments—such as that of the “neomort”—flesh out the argument.

Historical examination of attitudes to cadavers provides a context for this work. It is brave and noteworthy to describe explicitly our fearful subjective response to dead bodies. I would unrecommendedly recommend this chapter alone to medical students to medical sections. It is a humanising explanation of the heritage and necessity of undertaking postmortem examination and of learning anatomy by dissection. Jones then advances another strong contention: that the use of unethically research data and results constitutes moral complicity. He discusses contentious research derived from autopsies and wartime experiments, as well as touching on legal issues such as whether the body and its parts can be regarded as property.

The response to indigenous concerns about archaeological finding is that the body is “dead”. Jones manages to balance, on the one hand, strong arguments for advancing knowledge in science and anthropology, and on the other, the interests of indigenous peoples in respecting ancestors. The discussion of organ transplantation policies and the incipient ethical dilemmas of new technologies is generally solid, but occasionally fails to accommodate the full range of opinions. Given the broad remit of the field, Jones does well to cover the many hypothetical situations which may be expected.

In discussing brain death, Speaking for the Dead re-introduces the perspective of the cadaver, the person he or she was previously, and other stakeholders. These viewpoints, in defining brain death, frequently become subsumed to technical neurophysiology and philosophical argument about personhood, selfhood and consciousness. Jones makes more action guiding points, and thus his discussion is more clinically relevant than most other debates about brain death.

Finally, Jones expounds on his particular expertise, embryology, and specifically addresses brain birth. His arguments are based upon careful study and are highly pertinent. I hope they will be heeded.
Speaking for the Dead ranges far more widely than its title would suggest. Gareth Jones has covered a neglected area thoroughly. Moreover, he has integrated myriad tangential ethical problems into his discussion. Ramifications for the fields of research ethics, medical education, anthropology and policy are significant. Questions raised for the future are numerous, and Jones provides a compelling, well argued and consistent framework from which to address these problems. I would recommend this book to a broad audience—laypersons, doctors and philosophers—for its simplicity, eloquence and viewpoint. It is a thought provoking work, and engrossing to read.

D Sullivan

The American Medical Ethics Revolution


Codified moral medicine is an acute to moderately intractable problem well worth waging in the morass of moral idealogy, and a rampart that should be strengthened continually, rather than dismantled. The notion of medical professional self-regulation, by means of codified medical codes of ethics, was actually conceived in Britain, by Dr Thomas Percival, but born in America. The American Medical Ethics Revolution, through the medium of a tetrad of editors and a stellar collection of luminaries, display the pedigrees of codified American medical ethical thought back to its earliest progenitor: the primordial 1847 American Medical Association (AMA) code of ethics. The volume deftly handled academicians vividly the medical ethical dimension of the practice of medicine in America, and reveals the sharp contentiousness underlying American medical ethics, as well as the acute timelines of the volume.

The rich blend of varied viewpoints culled by the editors was delivered, originally, as papers at a conference in Philadelphia, PA, in March 1997, intended to commemorate the sesquicentennial of its pristine code of ethics. The ensuing volume ramifies into branches of good writing and philosophic musings appertaining to American medical ethics, reaching from the far past to the uncertain future. The volume is comprised of 20 chapters and includes notable appendices, showing the evolution of AMA principles and codes of ethics, from 1847 to 1997. The thoughtful ruminations on the evolution of American medical ethics reflect the crisp thinking of noted scholars drawn from diverse fields, including: ethics, law, public policy, philosophic history, and sociology.

The AMA code of ethics has a history of dissonance, albeit of continued vitality. The lineaments of the code have shown the ability to evolve, in response to professional and lay challenges. Although today, in America, medical ethical issues are possibly more beguiling than ever, some may opine that the code is really an anachronism which offers a mere patina of relevancy, and really nothing more than a facade of enforceability. Rigorous debate about its continuing vitality and relevance is certainly a very healthy exercise. And, it is in the realm of stirring, informed debate and discussion that the volume particularly excels.

Three chapters, for example, proffer a thought-provoking, trichotomy of views concerning the singular question: who should control the scope and nature of medical ethics? Several chapters examine the relevance and adequacy of the traditional paradigm of codified, collaborative medical ethics in the context of particular, contemporary challenges to American medical ethics, relating, for instance, to “alternative medicine”, managed care, and the challenge of providing universal access to health care, given limited resources.

The lengthy time continuum of the volume encompasses forward-looking comments on future challenges to traditional medical ethics, involving, for example, molecular medicine. Given the uncertain role of ethics in the unfolding genetics revolution, it cannot be gainsaid that it is timely and potentially salutary, to ponder, in an informed intellectual sense, whether codified ethics can favourably help guide the future of biomedicine.

The recondite nature of this volume is well tailored to suit the curiosity of academically inclined readers interested in medical ethics, both in America. Its abstruseness, however, is ill tailored to fit the lay reader; and may even fall outside the ken of comfort of some clinicians. In this respect, the volume is ineffectual as an educational conduit for the possible linkage of professional ethics with broader societal ethics.

Withal, the volume indubitably is a beacon of superb scholarship, illumining the path to moral rectitude, and barriers along the way, for academicians.

L Usyeh

Gene Therapy and Ethics


Gene therapy research and its clinical application raise a large number of ethical, legal, and social questions. Many of these are discussed in Nordgren’s anthology. The contributions come from a number of different disciplines, including bioethics, genetics, social science, and theology, and are divided into five main sections (following a short introduction): scientific aspects of gene therapy; the history of, and prospects for, gene therapy; conceptual issues; gene therapy in a German and Japanese context, and a section on the uses of gene therapy in relation to, for example, testing and screening. The contributions are quite diverse and mostly well worth reading. From the perspective of medical ethics, the contributions by LeRoy Walters, Eric Juengst, Karen Labeqcz, Nikolaus Knopffler, and Christian Munthe are of particular interest.

Walters’s contribution focuses in part on the issue of eugenics. He defends a voluntary germ-line gene therapy programme as a means of reducing the transmission of genetic diseases to future generations. In the context thereof he points out, in terms of targeted diseases or deviations, between past xenogenetic programmes and the sort of germ-line genetic intervention programmes that would probably be run today. Walters also discusses the difference between gene therapy and genetic enhancement. He thinks the distinction is vague. Eric Juengst undertakes the task of clarifying the distinction, discussing three accounts of it. These appeal to the goals of medicine, the notion of species-typical functioning and particular concepts of disease, respectively. Juengst argues persuasively that none of these distinctions bear moral weight. For instance, he points out that there are medical cases of treatment leading to above-species-typical functioning that seem obviously morally desirable (for example the use of gene therapy to empower the immune system to eliminate cancer cells). Juengst, however, is not critical of genetic enhancement, and there are some instances when his concern that genetic enhancement should not involve complicity with unjust social biases and Labeqcz’s views.

Labeqcz argues that the concept of therapy presupposes a distinction between normal and abnormal. How that distinction is drawn often depends on power structures in society and, hence, is not necessarily based on whether being unusual in some particular respect makes one worse off. An analogous gene therapy which targets perceived abnormalities, such as dwarfism, may not benefit anyone. It may simply make people more alike. Labeqcz suggests that if disability is a socially constructed difference, then social reactions to people who differ from the “genetic norm” that needs to be changed, not the differing individuals. It is not clear why this should be thought to follow. In our society, it seems to be the latter option which each of us is well off to the same extent but there is less human heterogeneity.

In his contribution, Nikolaus Knopffler claims the Kantian idea of human dignity, and treats it as the fundamental principle of bioethics. Roughly, in his view this idea implies that, whereas somatic gene therapy is morally unproblematic, germ-line gene therapy and germ-line enhancement are morally unacceptable. Knopffler does not explain why, exactly, this follows. At one point he seems to suggest that the fact that we have no common grounds for determining which enhancements are desirable implies that enhancement violates the Kantian principle, but such irresolvable disagreements simply seem beside the point.

In an interesting article, Christian Munthe convincingly argues that there is no morally relevant difference between genetic interventions involving the treatment of a particular individual and genetic interventions involving the exchange of the genetic information from one person to another. Examples of the latter sort of intervention include the preselection of embryos based on preimplantation genetic diagnosis.

K Lippert-Rasmussen

Creating Accepting Communities

S Dunn. MIND [National Association for Mental Health], 1999, £9.99 (£1 p+p), pp 181. ISBN 1874690871

The government’s social exclusion unit (SEU) was established to help individuals, groups, and regions overcome deprivation and discrimination resulting from a combination of problems, including unemployment, poor
quality housing, low income, lack of educational training opportunities, bad health, and family breakdown. Such difficulties are commonly experienced by people with mental health problems who also have to cope in a society which alienates and rejects them, barring us from every aspect of community life. Remarkably, even the SEU’s remit excludes consideration of the obstacles to social inclusion faced by those with a psychiatric diagnosis.

Creating Accepting Communities is the final report of an inquiry commissioned by MIND, which looked at the nature and extent of social exclusion experienced by people who use mental health services in Britain. The inquiry panel received written and oral evidence from a wide range of individuals and organisations, including mental health practitioners, high street retailers, groups working within the voluntary sector, and, importantly, service users.

The book is clearly written and the material well organised into four main chapters, each of which ends with a useful summary of the key issues raised. Quotations from witnesses are used extensively throughout the narrative, giving real meaning to the findings, and to participants a sense of “ownership” in the report.

The first chapter summarises evidence presented to the inquiry on how a psychiatric diagnosis can exclude people from a range of social and everyday significant areas such as employment, education and training, aspects of daily life (that is, access to goods and services, social networks, etc), and empowerment within mental health services. The panel found widespread evidence of social exclusion and dismissed claims that this was simply the result of poverty. Instead, they argue that while policy initiatives should focus on addressing the material circumstances of service users, they should also work towards creating greater social cohesion or social inclusion.

A range of ethical aspects associated with social inclusion is briefly but coherently discussed in chapter 2. In particular, inquiry evidence is used to evaluate the relationship between individuals and their wider community, and to address the following questions: how do service users judge the value of people with mental illness? How does society differentiate individual “badness” from “mental illness”? How should risk be defined? What is meant by the participation and empowerment of service users? Essentially, the findings support the basic need to recognise the absolute value of individuals and to acknowledge that any ethical approach to social inclusion needs to balance this against existing social forces: differences can only be resolved through the participation of everyone involved.

Chapter 3 discusses a range of initiatives that have been set up to promote social inclusion in various areas of work, education, the arts and the media, daily living, and the mental health services. The panel highlighted three areas where more work should be done to improve social inclusion: the development of new initiatives based on inter-agency cooperation, legal and policy-based reforms at national level and the promotion of more intensive public education programmes on mental health. Based on this inquiry evidence, chapter 4 presents a series of recommendations aimed at directing social progress “from exclusion to cohesion”.

In general, the report raises the profile of a wide range of issues concerning social exclusion and provides an informative overview of current policy and practice initiatives. Unfortunately, because the book’s remit is so wide, its depth of analysis is compromised, leaving unchallenged some very difficult ethical barri-

For example, little is currently known about the nature and extent of interactions between people with mental health problems and the law; “us” and “them” and the consequent implications of the promotion of a society based on “inclusive diversity," particularly in the face of: 1) growing public demands for more zero tolerance initiatives; 2) the threat of new legislation designed to exclude those with a serious personality disorder, those who fail to comply with medication while living in the community, and those who are disruptive in schools; 3) media campaigns provoking street demonstrations against groups the media feels society should no longer tolerate, and 4) employment practices which measure individual value in terms of productivity to the point whereby even mental health services lack confidence in service users’ abilities.

Ultimately, the problem of analytical depth is a methodological one that requires the development and integration of research initiatives at both the micro and macro levels of social inquiry. Moreover, these observations should not detract from what is an excellent report and an important reference point for anyone interested in understanding the social inclusion of people who experience mental ill health.

A Colombo

Priority Setting and the Public


As its title suggests this book’s main area of inquiry is the rationale for, and methodology of, public involvement in priority setting. Mullen and Spurgeon set out to evaluate a number of assumptions and hard issues in priority setting. In doing so they have produced a volume that is both a useful introduction to this area and a worthy piece of research on an important theme.

They begin by contextualising the debate about priority setting within the recent history of health reform in the UK and other nations. This move enables them to give an analysis of considerable scope. They are not just interested in rationing and public involvement but also in questions about the level to which the UK National Health Service (NHS) ought to be publicly funded. Given the frequently stated assumption that rationing is inevitable it is very refreshing to read a book that grapples with the difficult, more primary question of whether rationing itself is in fact necessary.

They note that reform processes and initiatives in the health system have served to focus attention on the need for priority setting but that there is a need to evaluate carefully the basis of this need. The present level of funding that the NHS receives is a matter of choice and not simply a reflection of current necessity, as is frequently implied. They suggest that we should think carefully about the inevitability of rationing and our inability to pay and instead work out how to provide treatments that are of real benefit.

In chapter three they examine the basis for public involvement in priority setting. Given that many would think that public involve-

Catholic Ethicists on HIV/AIDS Prevention


This impressive and informative book deserves a wider readership than it is likely to get. Unfortunately there are still too many people who consider they have no need to read anything about the virus as it will, to their way of thinking, never touch them. In addition there will be those who think that a volume by Catholic ethicists will be too narrow in outlook to be worthwhile. Both sets of people are very much mistaken. While the authors do not suggest that there is no cure nor is there likely to be and sooner or later it will affect, let alone infect, millions across the world. On the second count readers will be surprised and energised by the clear and honest debate concerning the teachings of the Catholic Church.

The first and longest section is made up of a series of case studies ranging from needle exchange in Puerto Rico, to confronting social stigma in Uganda, and matters relating to confidentiality in Australia. The second consists of seven chapters covering fundamental moral issues for HIV prevention; the chapter by Lisa Cahill (Boston, USA) on AIDS, justice, and the common good and the one by Paulinus Odozor (Atakurku, Nigeria) on Casuistry and AIDS, are particularly worthwhile. Kevin Kelly (Liverpool, UK) provides the conclusion. The third theme would do well. New Directions in Sexual Ethics, (Geoffrey Chapman, 1998) in which he highlights what is undoubtedly of paramount concern in developing countries namely poverty, the subjugation of women and sexual violence, is well worthwhile.

The most obvious moral issues are those surrounding the use of condoms but they are not the only ones. What if an infected person refuses to tell his or her partner of their status? Is any duty incumbent on the doctor treating...
the positive person to inform the partner? Where does confidentiality begin and end? One of the saddest cases, and not as rare as it may seem, is of a married couple in Italy, both infected, who want to have a child. Will the child also be seropositive? Will one or both parents live long enough to look after the child? Who else should know of the situation? The Catholic Church has always had high ideals even if many of its adherents, including some in positions of power and authority, have not lived up to them. Those ideals cover not just areas of chastity and fidelity but also those of charity and truth where each one of us has to strive constantly to live up to a more responsible morality for living. The church has particularly strong teaching on fidelity in marriage and against premarital and extramarital sex. It is important to recognise the connection between this strong teaching and the basic values of family life and the worth of the individual, on the one hand and, on the other, the abuses that arise from pressures on innocent girls and women, particularly in some cultures. A universal approval of condom use would readily reduce many of our greater ills and would enable us to consider how we can work towards the time when married couples have sufficient education and knowledge to work out for themselves the right use of conscience with regard to their sexual lives. Equally there is an appeal when the situation is so far from obvious: we have to remind ourselves frequently that we are fallible human beings with free will. This book gives a long way towards enabling the reader to consider and ponder at some considerable depth, a variety of dilemmas and questions.

In so many countries, including our own, a conspiracy of silence, of denial, has grown up in respect of AIDS. It is only when HIV is looked at objectively and dispassionately, regardless of the moral stigma that so often haunts those affected by the virus, that the real work of prevention will occur. Education alone is not enough. Only when we understand what the virus is, how it is passed on, what it does to individuals and to families—not least those of charity and truth where each one of us has a responsibility for others in this desperately needy world. In our multicultural medical practices all doctors need to be more aware of HIV and its consequences.

D Bell

From Chance to Choice: Genetics and Justice


With over 10 000 bases of DNA being sequenced around the world per minute, it is vital that ethical discussion continues to keep pace with genetic research. This contribution by four top theorists in bioethics carefully considers the implications of the many ways genetic information will influence human health and reproduction, by considering “the most basic moral principles that would guide public policy and individual choice concerning the use of genetic information in a just and humane society” (pages 4–5).

Proceeding with the themes of rights, justice, and harm, problems addressed by the authors include: the significance of the moral difference between treating genetic disease and altering personality characteristics; whether the utilisation of prenatal interventions to avoid disability discriminates against the disabled, and who should have control over the utilisation of this technology.

The main focus of the work is upon the future of genetics, however this is framed within an “ethical anatomy” of eugenics, in which the inappropriateness of past practices is considered. It is argued that the wrongs of eugenics (broadly, a denial of freedom) must be recognised when considering what an ethical solution to each problem in genetics, must be constituted, that wanting to provide future generations with genes that could contribute to their lives going better is not necessarily unpalatable. It is vital, however, that any such procedures are pursued justly.

After moving through several topical themes in genetics (which are highlighted in the introduction by the presentation of several futuristic genetics scenarios), the final chapter of the book draws out the major principles that should be used in policy-making about genetic technology.

Among the arguments advanced throughout are claims made in support of a functional perspective for the distribution of genetic technology is acceptable, and that this may also theoretically be applied to non-therapeutic interventions. It is preferable in this case for social institutions to be designed which do not exclude people who are worse-off, and for plurality in views of personal assets and the good life to be protected (chapters three and seven). In chapters four and five it is argued that the boundary between treatment and enhancement does not always coincide with what is acceptable and unacceptable, however, it is a good starting point for what the obligations of the state should be in delivering health care. The authors found no “reason to object in general to using genetic influences any more than environmental ones” (page 202), however concerns about both fairness in the distribution of this technology and medical risk should still be recognised. Chapter six explores in more detail the idea of reproductive freedom in preventing or allowing harm to children, and discusses ways around the “non-identity” problem to illustrate a basis for obligations to prevent harm. Another effect of this obligation, however, is that parents should strive to benefit their children and oblige them to live a life within the limits of a requirement for these benefits are addressed in chapter seven, through an analysis of several disability-rights critiques of genetics.

This is an excellent book that immediately engages the reader—in a way that looks around the world examples, a recognition that there may be more than one ethical solution to each problem in genetics, and an articulation of the limits of ethical theory. Although each author has contributed to different chapters, the book does not suffer from an inconsistency of style. It is worthwhile to read it from beginning to end, as subtle connections between many apparently unrelated issues begin to emerge. It will, however, also be useful as a tool for anyone interested in obtaining clear analysis of topical issues in genetics. An extremely comprehensive table of contents also makes the book easy to navigate.

Overall, this book provides new insights on many important questions in genetics, but it also elegantly illustrates the inherent complexity in issues that have arisen and will continue to arise when genetics, reproductive technology and parenting practices coincide.

A J Newson

Living and Working with the New Medical Technologies: Intersections of Inquiry

Edited by M Lock, A Young, A Cambiogso Cambridge University Press, 2000, £15.95/US$24.95, £42.50/US$69.95, pp 295. ISBN 0521652103

This collection of essays is the outcome of a conference addressing the problems arising from the conjunction of medicine and the humanities with the ever more pressing concerns of bioethics. Since this is a fairly recent development the introduction summarises the argument about what constitutes science and whether it is culturally located. Throughout this well-produced book there is room for discussion and dispute as is inevitable in any interdisciplinary work.

The first part of the book looks at the theoretical foundations. Rheinberger discusses the enormous change in the ability to control the biological make up of mankind that molecular biology makes possible. He will effectively end the nature/culture juxtaposition. These deliberations are then placed into a philosophically general perspective by Rabinow. Part two moves into the real world of laboratories and clinics. Lowy discusses the important role that the concept of controlled randomised clinical trials plays in introducing scientific rigour into medicine (in fact this preceded molecular biology by many years), leading ultimately to the development of centralised, multicentre trials of cancer drugs involving close collaboration between research labs, industry and clinics, this in turn leading to greater standardisation of the practice of medicine and the treatment of diseases. A comparable case is the search for anti-AIDS drugs by desperate patients, which has become an interchange between pharmaceutical firms and governmental agencies dependent on the cooperation of patients willing to take part in the trials. Thus politicalisation begins to move the debate out of the purely scientific arena; and AIDS activists have gained a definite, though limited, influence which highlights the social science component of modern medicine. Clinical interviews in relation to pathological investigations show that patients have a part to play in making both medical and surgical decisions, which in turn depend on wider considerations of cost and efficacy. Throughout it is emphasised that decision making in diagnosis and subsequent treatment depends upon various kinds of authority, literary, cultural and political, people’s own experience of previous sociology or philosophy of the science in question. Young’s discussion of post traumatic stress disorders also emphasises fashion in psychological diagnosis and the sociocultural location of interpretation of mental states.

In part three Kaufert examines breast and cervical screening as techniques and airs the debate on whether such screening is cost-effective and at what price to individuals at risk from false positives. Looking at Down’s...
syndrome children, Rapp highlights the disjunction between technological advance in genetics and biotechnology and the human response of families who care for such children. A further chapter deals with “bio-mental” or “bio-social” conditions, notably MCS (multiple chemical sensitivity) and finds that in the light of conflicting interests and under-funded research any explanation of these sociomedical disorders is likely to be tentative and locally determined. The last two essays deal with organ transplantation and unpack the problem of the dichotomy of the “gift of life” that organ donation from brain dead persons presents, versus any sentiment concerned with keeping dying patients intact—a dilemma that is much felt even within the medical profession. Approaches differ between the US and Japan. The ethical dilemma is compatible but at present there are various solutions. Ethics are generally more implicit than overt but it is agreed that they are diffusely socially determined. The final essay, which considers the ethics involved in transplant procuring whether by gift selling or cadaver donation, finds that regulations aimed at safeguarding certain rights may themselves infringe customary perceptions of what is moral. Some of the problems would benefit from an anthropological approach that takes account of the specificity of small local communities.

There are no final answers in this book, but the at times diverse essays bring together highly topical discussions about the rights and wrongs of a world that is just opening up.

C R Barber

Animals in Research: For and Against


The use of animals for the purpose of scientific research is an emotive subject. The moral arguments often exhibit polarised positions: the scientific demand for absolute freedom of research, and the abolitionist demand for a total ban on all animal experiments. At one extreme are those who argue that research on animals is essential in the battle against disease, and on the other extreme it is argued that the cost in terms of animal suffering is too high and that if experiments were prohibited medical researchers would find some other means of ensuring scientific progress. The rhetoric employed is also suggestive of a polarity: experimenters are accused of cruelty and indifference, whereas campaigners on behalf of animals are accused of irresponsibility and insensitivity towards the wellbeing of humans. Yet to ask which side is right is to betray a misunderstanding of the complex nature of the debate, in which a plethora of interlinked ethical and scientific issues find expression in a wide spectrum of viewpoints.

One of the strengths of Animals in Research is that Grayson recognises the complexity of this issue, and in the opening chapter, which surveys the historical and philosophical sensitivity and find expression in a wide spectrum of viewpoints.

In this book, H Tristram Engelhardt Jr outlines his interpretation of Christian bioethics. His branch of Christianity, termed “traditional Christianity”, is described as “the Christianity of the first millennium”. Authority is derived from the church fathers and their works are continuously cited and from the church communi-

The Foundations of Christian Bioethics


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Kierkegaard, as well as an introduction to the ethics of Orthodox Christianity. On balance, however, this book will perhaps seem somewhat irrelevant to contemporary bioethicists, although it may prove of more interest to theologians, especially those of the more conservative persuasion, such as the emerging school of radical orthodoxy. Ultimately, the difficulty with Engelhardt’s position is communication. His rejection of “liberal cosmopolitanism” leads to an unwillingness to compromise, which makes it difficult for those from the “liberal cosmopolitan” world-view to hear his points; this is somewhat problematic given that his intended audience is the academic community.

H Widdows

NOTICE

A Cross-cultural Dialogue on Ethical Challenges in Healthcare

An international conference on health care ethics, A Cross-cultural Dialogue on Ethical Challenges in Healthcare, is to be held in Abu Dhabi, the capital of the United Arab Emirates, from 10–13 March 2002. It is being organised by the UAE Ministry of Health. Co-sponsors of the conference include the World Health Organization (WHO), the Islamic Organization for Medical Sciences (IOMS), the International Association of Bioethics (IAB), the Emirates Medical Association (EMA), and the Gulf Center for Excellence in Ethics (GCEE).

As the first such conference in the Arab and Muslim world, it aims to bring together scholars and experts from around the world to address a wide range of ethical and social considerations in the planning and delivery of health care.

The objectives of the conference are to: promote a cross-cultural dialogue towards agreement on universal standards of health care ethics; highlight the Islamic world’s contribution to this process; enhance awareness and knowledge of contemporary ethical issues in health care, and to build national and regional capacity to address complex bioethics issues against the backdrop of rapid advancements in the health sciences.

The conference will examine a broad range of contemporary health care ethics topics including: current controversies in research involving human subjects in developing countries; ethical decisions and considerations in clinical practice; social issues in genomics; strategies for allocating scarce resources; access issues in health systems, and building a bioethics capacity and infrastructure in the UAE, Gulf region, and Arab world.

For copies of the conference programme and registration forms please contact: Dr Basil A Badir, Conference Coordinator, Ministry of Health, PO Box 26094, Abu Dhabi, United Arab Emirates. Telephone: + 971(2) 6330186 and +971(50) 6325110; fax: +971(2) 6321878 and +971(2) 6349225; email: moh_basilb@hotmail.com and ethics_conf@moh.gov.ae; Website: http://www.uae.gov.ae/moh/start.htm

CORRECTION

In the December 2001 issue of the journal the Book reviews section was incorrectly headed Letters. We wish to apologise to readers for any inconvenience this error caused.