

## Guest editorial

# Demystifying bioethics – a lay perspective

Sir Patrick Nairne *Nuffield Council on Bioethics*

For most of us bioethics is a grey and forbidding word: not a common subject for casual chat in a bar parlour. But most of us are also aware of advances in biomedical science which are both exciting and potentially alarming, and they are making bioethics increasingly important – touching closely, sometimes intimately, on the lives of us all.

This winter, the Nuffield Council on Bioethics will be publishing substantial reports on two important subjects: genetic screening and the uses of human tissue. They should catch the attention of doctors and clinical researchers. The major organs of the media may comment. The reports will, I hope, be welcomed by readers of this journal. But those for whom these questions may often matter most are unlikely to read the reports unless they are written and disseminated with their interests in mind.

Medical ethics is still largely preserved as professional property. For doctors of the past it may have been no more than their Hippocratic Oath, and the self-discipline to avoid either seducing the female patient or being seduced by the pharmaceutical industry. For a doctor today there needs to be an understanding at least of the four high-sounding, and sometimes conflicting, principles of medical ethics – non-maleficence, beneficence, justice and autonomy – meaning more simply: do not hurt the patient; provide the best treatment you can; be fair to all patients in the treatment you offer; respect your patients and listen to what they have to say. But many of us, as patients or the families of patients, are unsure what to say. We may be assertive about our rights; but we are not clear what autonomy is or means when applied to our clinical condition and the ethical questions which that may raise. The position vividly put by Enoch Powell in his book, *Medicine and Politics* (1) can still ring true:

‘... the patient and the patient’s relatives are face to face not with the doctor as an individual but with the panoply of an institution, physical, corporate and social. All the romance, wonder and terror of modern medical science is associated with the hospital and its deep recesses: the hospital has prestige and inspires awe. For good reason, the hospital patient is often for one reason or another helpless.’

The media, especially television programmes, now regularly expose us to hospital life and the world of medicine; but the ‘wonder and terror’ of advances in medical science have not diminished. When it comes to themselves, patients are usually content to trust general practitioners or consultants to exercise ‘beneficence’ and ‘non-maleficence’ as they judge best. As to ‘justice’, we may grumble, from time to time, at the injustice of NHS waiting times, and we may occasionally be shocked by media reports of how some patient has been treated. But we have not, at least in the past, thought of these matters, which may reflect a variety of causes, as issues of medical ethics which we need to understand.

The fact is, however, that we are all necessarily involved – and increasingly so with bioethical questions which are likely to touch more of us, and perhaps all of us, in a way that was inconceivable, or scarcely conceived of, in the past. Events of this year bear witness: the trial of Dr Cox at Winchester and the complex ethical issue of ‘assisted death’; Tony Bland of the Hillsborough disaster and the ethical implications of the persistent vegetative state. The widening impact of HIV and AIDS has created some acute ethical problems of clinical confidentiality; the advances in genetic research, and in particular the Human Genome project, are posing ethical questions of great potential difficulty. What, for example, should be the criteria for genetic screening? Is it right to screen for conditions for which there may be no effective therapy?

In the Caledonian Research Foundation’s 1993 prize lecture Professor Galjaard of the Erasmus University, Rotterdam, spoke of the ‘fantastic advances’ in gene technology, but expressed concern at exaggerated claims and expectations. He was also reported as pointing out that geneticists knew nothing about how individuals would react to being told that in 20 years time they would be likely to suffer from cancer or a psychiatric disease (2).

A year earlier an article in *The Economist* had remarked about genetics (3):

‘Genes are blamed for everything from cancer to alcoholism. People worry about being made ineligible for jobs because of disease susceptibilities they

never knew they had; fetuses are aborted because of faults in their genes ...’;

Thus we need to understand – and, if we are to be able to exercise personal autonomy, to be helped by clinicians to understand – that bioethics can no longer be only a matter of professional responsibility for clinical practitioners and researchers or a subject for academic study or medical journals. It is on the agenda for all of us.

That has been fully recognised by newspapers, magazines, and the wider media. There have been many responsible press articles, and also television and radio programmes, which have presented and discussed what has emerged, or may yet emerge, from genetic research. But there is, at the same time, unavoidable scope for dramatising possibilities or potential developments affecting all of us in a manner more likely to alarm than educate. And headlines are designed to catch the reader’s attention. For example, *The Times* headed an article this year (4):

**‘IGNORANCE MAY BE BETTER. DO YOU WANT TO KNOW IF YOU WILL GET BREAST CANCER?’**

In May headlines respectively from the *Mail on Sunday* (5) and the *Daily Express* (6) ran:

**‘HAS BRITAIN REALLY MADE HUMAN CLONES? APES WERE USED FOR SURROGATE MOTHERS’** and

**‘YOUR BABY IS GOING TO BE HOMOSEXUAL, SO WE WILL ABORT HIM. SCIENTISTS’ NIGHTMARE VISION OF DNA REVOLUTION’.**

All this illustrates the background to an approach by senior researchers three years ago to the Nuffield Foundation urging that the pace of biomedical and biological research was throwing up important ethical questions which needed to be urgently explored. Were they entirely new questions or old ones in a new guise? Were there potential issues of public policy? Public concern was being aroused by the media, and there was an evident need for responsible and wider discussion and understanding. The Americans had led the way in 1978 with the creation of the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research; a National Consultative Committee had been established in France in 1983; and many other governments were getting into the biomedical ethical act. A major initiative was now needed in this country.

Soundings were taken in Whitehall. Although it had set up *ad hoc* inquiries – for example, the Warnock and Polkinghorne Committees (7) – the

government was not contemplating any inquiry on the wider scale envisaged by the Nuffield Foundation. And so, after a prolonged period of consultation, the Nuffield Council on Bioethics was established in July 1991, taking a place alongside other UK bioethics institutions. Its terms of reference specifically included the task of ‘promoting public understanding and discussion of the major ethical questions raised by recent advances in biological and medical research’.

After surveying the field of research and establishing its initial agenda priorities, the council set up two working parties – on genetic screening, and on the medical and scientific uses of human tissue. It was quickly evident that their work was timely. In June 1991 the US National Institutes of Health had opened up the challenging issue of patent applications relating to DNA fragments. In the words of a weekend paper report two months later about ‘The new genetics’ (8):

‘Not since the space race have so many scientists been engaged in one revolutionary project – and this time they are all on the same side. Their aim is to map the entire genetic blueprint. If they succeed, the face of medicine will never be the same again.’

The council and its working parties are engaged on an exacting task. Their reports will set out the progress in research, and the practical professional developments that are being introduced or are likely to be available fairly soon. They will define the relevant ethical issues and principles – relating, for example, to the central questions of privacy and confidentiality, the ownership of tissue, and the broader issues of how much people need to know or want to know, if ethical requirements are to be met. But, for the purpose of wide and responsible discussion of these issues in the media and at public meetings, it will also be important to offer at least some realistic illustrative account of the likely problems affecting people and their lives and of the factors which may influence and assist the decisions which different individuals in different circumstances may choose, or be compelled, to make.

I hope that this approach will lead to valuable reports which will be welcomed by all those who supported the establishment of the Nuffield Council. But what we publish, at least on genetic screening, must also be accessible – perhaps in a shorter and more popular form – to the general public. This would be a step towards demystifying bioethics. It should assist in widening understanding and stimulating further discussion in the media, and at the seminars and open meetings which we hope to be able to arrange.

We must not claim too much for what we shall achieve. Bioethics will continue to look grey and forbidding to those who are strangers to the personal questions it poses. But, if the Nuffield Council’s

plans for dissemination and discussion can be carried into effect, we should succeed in enlarging public knowledge, and also in promoting the temperate climate of understanding that is needed as a response to the further scientific advances which lie ahead.

Sir Patrick Nairne, GCB, MC is Chairman of the Nuffield Council on Bioethics, was Permanent Secretary to the Department of Health and Social Security from 1975-1981 and is Chairman of the Institute of Medical Ethics Working Party on Ethics and AIDS.

## References

- (1) Powell E. *Medicine and politics*. Tunbridge Wells: Pitman Medical, 1966, revised 1976.
- (2) Wojtas O. Geneticist slams idea of science to cure all. *The Times higher educational supplement* 1993 Apr 23.
- (3) Anonymous. The tiniest transplants. *The economist* 1992 Apr 25: 111.
- (4) *The Times* 1993 Mar 2.
- (5) *Mail on Sunday* 1993 May 2.
- (6) *Daily Express* 1992 May 12.
- (7) *The Warnock report: Report of the committee of inquiry into human fertilisation and embryology*, chaired by Dame Mary Warnock, London: HMSO, 1984 (Cmnd 9314). *The Polkinghorne report: Review of the guidance on the research use of fetuses and fetal material*, chaired by the Revd John Polkinghorne, London: HMSO, 1989 (Cm 762).
- (8) Highfield R. Why life will never be the same again. *Sunday Telegraph magazine* 1991 Aug 17: 30-31.

## News and notes

### Philosophical Ethics in Reproductive Medicine

The Third International Conference on Philosophical Ethics in Reproductive Medicine will take place at the University of Leeds from April 18-21 1994. Invited speakers include: Professor Baruch Brody (USA), Professor Margaret Brazier (Manchester), Professor Colin Campbell (Nottingham), Professor Heleen Dupuis (Holland), Professor John Harris

(Manchester), Professor Berndt Kjessler (Sweden), Dr Theresa Marteau (London), and Professor Zbigniew Szawarski (Poland).

For further information please contact: Mrs Hilary L Thackray, Department of Continuing Education, Continuing Education Building, Springfield Mount, Leeds LS2 9NG.

## News and notes

### Medical Screening: the Way Forward

Medical Screening provides many opportunities for the prevention of disease and handicap. What can it offer and what are its limitations? Based on several case studies, *Medical Screening: the Way Forward*, organised jointly by the *BMJ* and the *Journal of Medical Screening* is a one-day conference to be held on 26 January 1994 at the QE2

Conference Centre, London to examine the medical, scientific, ethical, social, psychological and economic aspects of screening.

For more information contact: Pru Walters, BMA Conference Unit, BMA House, Tavistock Square, London WC1H 9JR. Telephone: 071 383 6605. Fax: 071 383 6400.