CHAPTER ONE

Gaining autonomy and losing trust?

1.1 CONTEMPORARY BIOETHICS

Bioethics is not a discipline, nor even a new discipline; I doubt whether it will ever be a discipline. It has become a meeting ground for a number of disciplines, discourses and organisations concerned with ethical, legal and social questions raised by advances in medicine, science and biotechnology. The protagonists who debate and dispute on this ground include patients and environmentalists, scientists and journalists, politicians and campaigners and representatives of an array of civic and business interests, professions and academic disciplines. Much of the debate is new and contentious in content and flavour; some of it is alarming and some misleading.

The first occasion on which I can remember a discussion of bioethics – we did not then use the word, although it had been coined[1] – was in the mid-1970s at a meeting of philosophers, scientists and doctors in New York City. We were discussing genetically modified (GM) organisms: a topic of breathtaking novelty that was already hitting the headlines. Towards the end of the evening an elderly doctor remarked, with mild nostalgia, that when he had studied medical ethics as a student, things had been easier: the curriculum had covered referrals, confidentiality – and billing. Those simpler days are now very remote.

[1] The Kennedy Institute in Washington DC was founded in 1971 with the full name 'The Joseph and Rose Kennedy Institute for the Study of Human Reproduction and Bioethics'. See W. T. Reich, 'The Word 'Bioethics': Its Birth and the Legacies of Those Who Shaped It', *Kennedy Institute of Ethics Journal*, 4, 1994, 319–35.

During these years no themes have become more central in large parts of bioethics, and especially in medical ethics, than the importance of respecting individual rights and individual autonomy. These are now the dominant ethical ideas in many discussions of topics ranging from genetic testing to geriatric medicine, from psychiatry to *in vitro* fertilisation, from beginning to end of life problems, from medical innovation to medical futility, from heroic medicine to hospices. In writing on these and many other topics, much time and effort has gone into articulating and advancing various conceptions of respect for persons, and hence for patients, that centre on ensuring that their rights and their autonomy are respected. Respect for autonomy and for rights are often closely identified with medical practice that seeks individuals' informed consent to all medical treatment, medical research or disclosure of personal information, and so with major changes in the acceptable relationships between professionals and patients. Medical practice has moved away from paternalistic traditions, in which professionals were seen as the proper judges of patients' best interests. Increased recognition and respect for patients' rights and insistence on the ethical importance of securing their consent are now viewed as standard and obligatory ways of securing respect for patients' autonomy.[2]

Rights and autonomy have played a lesser, yet still a significant, part in other areas of bioethics, including even environmental ethics. For example, rights may be invoked in arguing for prohibitions on marketing unlabelled food products containing additives or GM crops or on adding chemicals to water supplies, with the thought that rights are violated where individuals cannot refuse, nor therefore choose, because they are kept in ignorance or unable to opt out. Agricultural regulations have been condemned as

[2] For a highly informative account of these changes, concentrated mainly on the US case, but with much that is relevant more widely, see Ruth Faden and Tom Beauchamp, *A History and Theory of Informed Consent*, Oxford University Press, 1986; for a sociological perspective see Paul Root Wolpe, 'The Triumph of Autonomy in American Bioethics: A Sociological View', in Raymond DeVries and Janardan Subedi, eds., *Bioethics and Society: Constructing the Ethical Enterprise*, Prentice-Hall, 1998, 38–59.

violating or as failing to protect animal rights, or farmers' rights to choose how to cultivate their land. Pollution controls have been attacked as violating the purported rights of individuals to conduct their lives and their businesses as they see fit.

We might expect the increasing attention paid to individual rights and to autonomy to have increased public trust in the ways in which medicine, science and biotechnology are practised and regulated. Greater rights and autonomy give individuals greater control over the ways they live and increase their capacities to resist others' demands and institutional pressures. Yet amid widespread and energetic efforts to respect persons and their autonomy and to improve regulatory structures, public trust in medicine, science and biotechnology has seemingly faltered. The loss of trust is a constant refrain in the claims of campaigning groups and in the press. In many developed countries, and particularly in the UK, there is evidence that mistrust of various professions, experts and of public authorities is quite widespread.[3]

This loss of trust is often ascribed to the supposed untrustworthiness of scientists and biotechnologists, even of doctors, and of those holders of public office who legislate for and regulate their activities. Medical professionals and regulators, politicians and civil servants, biotechnology companies and scientists, it is often suggested, pursue their own interests rather than those of patients or of the public. If true, these claims suggest that measures introduced (in part) to improve individual autonomy and to ensure that treatment and research do not proceed without informed consent have failed to secure trust, and may even have damaged trust. Perhaps this should not surprise us: increasing individual autonomy may increase the autonomy of those in positions of power, so adding to their opportunities for untrustworthy action and to others' reasons for mistrusting them. Perhaps reducing the autonomy of any agents and institutions who might act in untrustworthy ways would help to restore trust. Is some loss of trustworthiness and of trust an

[3] The MORI polls' website contains reports of numerous recent polls documenting lack and loss of public trust; see institutional bibliography (p. 205).

acceptable price for achieving greater respect for autonomy? Do we have to choose between respect for individual autonomy and relations of trust? None of these prospects would be particularly welcome: we prize both autonomy and trust. Yet can we have both?

1.2 MEDICAL ETHICS AND ENVIRONMENTAL ETHICS

The two principal domains of bioethics are medical ethics (broadly interpreted to include the ethics of bio-medical research) and environmental ethics. Autonomy and trust have played quite different roles in these two areas. The reasons behind these differences are instructive.

Much of medical ethics has concentrated on the individual patient, her rights and her autonomy; demands that medical professionals respect autonomy and rights have become a constant refrain. The implicit context of nearly all of this work is the medical system of a developed society with much hospital-based medicine. Topics such as the just distribution of health care within these medical systems, public health and global health distribution have been pushed to the margins in much of bioethics.[4] Perhaps these topics have been marginalised because individual autonomy is viewed as central to medical ethics.

Writing on environmental ethics has more often focused on public benefits and public harms. Here individual autonomy is quite often seen as a source of harms, and there has been a steadily increasing emphasis on the consequent need to limit individual autonomy. Standard examples of such controls include prohibitions on discharge of raw sewage or toxic chemicals, regulation of standards for vehicle emissions or building insulation and requirements for high safety standards in biotechnology. Contemporary discussions

[4] With notable exceptions. For an early example see Norman Daniels, *Just Health Care*, Cambridge University Press, 1985; a revised edition titled *Just Health* is forthcoming; also Thomas W. Pogge, 'Relational Conceptions of Justice: Responsibilities for Health Outcomes', in Sudhir Anand, Fabienne Peter and Amartya Sen, eds., *Health, Ethics, and Equity*, Clarendon Press, forthcoming. Questions of equity and fairness are generally more prominent in work on welfare, public health and health economics than they are in bioethics.

in environmental ethics seldom view the autonomous 'life-style' choices of individuals as adequate for protecting the environment. They increasingly highlight the importance of stewardship of the environment and argue that this requires public regulation and enforcement, sometimes international regulation and enforcement.

There are further and deeper reasons why individual autonomy has been less central in environmental than in medical ethics. Environmental ethics is fundamentally concerned with the treatment of life forms (above all of animals and plants), of groups and systems of life forms (such as ecosystems and populations), and with the importance of more abstract aspects of the environment such as species and the ozone layer, climate change and pollution. By and large, writing in environmental ethics has therefore tried to emphasise continuities between human and non-human parts of the natural world, and to claim for the latter some of the respect and concern traditionally thought important for the former. In claiming that the natural world is owed respect and concern, environmental ethicists have not viewed that world or its inhabitants as agents whose autonomy is to be fostered or whose consent to activities in which they are involved should be sought. Their ethical debates have therefore not been mainly concerned with agency and autonomy, with consent or anti-paternalism; rather their aim has been to detach notions such as rights, respect and concern from their historic association with conceptions of agency, persons and autonomy.

The distance between these two branches of bioethics is now diminishing. In part this is because several issues that link health and environmental concerns have become urgent. Discussions of GM crops, of food safety, of pollution and of animal welfare often link medical with environmental issues. The emergence of antibiotic-resistant strains of bacteria is a medical problem, for which poor agricultural practices may be partially responsible. Major environmental problems such as desertification, water shortages and air pollution all have serious health implications.

There is in any case more common theoretical ground between the two branches of bioethics than some suspect. Environmental

ethics is, perforce, addressed to human agents: they are the only possible audience for its prescriptions and its arguments. It therefore has to build on the same assumptions about human agency that are basic to medical ethics. Although environmental ethics has often repudiated 'speciesism', and with it failures to take the claims – supposedly the rights – of various non-human parts of nature (especially of non-human animals) seriously, it is unavoidably every bit as anthropocentric in its view of the audience for ethical reasoning as any other bit of ethics.[5]

It is therefore not surprising that medical and environmental ethics have found a common language by focusing on rights. The language of rights permits convergence in the vocabularies of medical and environmental ethics by bracketing many questions about agency and obligation in favour of a primary focus on recipience and entitlement. Medical ethicists view human rights, among them patients' rights, as securing the right sort of respect for human agents and their autonomy. Environmental ethicists see the rights of animals, and even of other parts of the natural world such as plants and landscapes, ecosystems and species, as securing protection and respect for the non-human world.

Fundamentally the difference between these two parts of bioethics is not that one endeavour thinks agency important and that the other thinks it unimportant, but rather a focus on different objects of ethical concern, on the differing claims that these make on agents, and on the differing part that relationships between individuals play in the two domains. In medical ethics it has become standard to stress the *distinctiveness* of human capacities for agency, and to stress capacities for autonomy, and so to emphasise the special ethical concern and respect to be accorded to persons, including patients, and the special importance of human rights. In environmental ethics the *similarities* between human and non-human

[5] See Peter Singer, *Animal Liberation*, Jonathan Cape, 1976, for a critique of speciesism; for the relation of anthropocentrism to speciesism see Tim Hayward, 'Anthropocentrism: A Misunderstood Problem', *Environmental Values*, 6, 1997, 49–63 and Onora O'Neill, 'Environmental Values, Anthropocentrism and Speciesism', *Environmental Values*, 6, 1997a, 127–42.

parts of nature have been stressed: the normative claims, supposedly the rights, of humans and other primates,[6] of humans and all non-human animals,[7] of humans and non-human organisms in general have been compared, even equated. Most medical ethics is avowedly humanistic, but environmental ethicists regard humanism as an ethically unacceptable form of species preference (speciesism). They may even see human rights, let alone human autonomy, as problematic sources of harm or indifference to other living creatures or to the environment. Humanism is commonly seen as part of the *problem* rather than of the *solution* in environmental ethics. Nevertheless, both medical and environmental ethics can be addressed only to those who can reason, deliberate and act; both debates must take agency, and therefore human agency, seriously.

Since autonomy has played so much larger a role in medical than in environmental ethics, I shall mainly choose my illustrations from debates in medical ethics. However, I shall also introduce a limited range of examples from environmental ethics, in order to shed light both on reasons why the two parts of bioethics have diverged and on some ways in which public health issues have been marginalised in medical ethics.

1.3 TRUST IN THE RISK SOCIETY

Although discussions in medical ethics and environmental ethics have diverged in many other respects, both have recently encountered similar crises. In both areas agents and agencies have found it hard to establish and to maintain public trust in their action and policies. The crisis has been particularly marked in the UK, but is evident in many other rich and technically advanced societies.

The targets of public mistrust have been widely discussed across the last thirty years both in sociological discussions of the

[6] See Paola Cavalieri and Peter Singer, *The Great Ape Project: Equality beyond Humanity*, Fourth Estate, 1993.

[7] The best-known work is still Singer, *Animal Liberation*; but see also Stephen R. I. Clarke, *The Moral Status of Animals*, Oxford University Press, 1977; Peter Singer, *The Expanding Circle: Ethics and Sociobiology*, Clarendon, 1981.

'risk society'[8] and in the media. Leading sociologists have noted that many technical and social practices – prominently among them medicine, science and biotechnology – have become larger and more remote, and are seen as more laden with hidden risks, and that fears have multiplied with the globalisation of economic and technical processes. The fears and anxieties of 'risk societies' focus particularly on hazards introduced (or supposedly introduced) by high-tech medicine and genetic technologies, by nuclear installations and use of agrochemicals, by processed food and intrusive information technologies.

Yet it is open to doubt whether most people in the richer parts of the world encounter risks that they can do less to control than earlier generations could do to control risks they faced. Traditional hazards such as endemic tuberculosis or contaminated water supplies, food scarcity and fuel poverty were neither minimal nor controllable by those at risk from them in the recent past, and are neither minimal nor controllable for those who still face them in poorer societies today.[9] The claim that richer societies have become 'risk societies' is a claim not about levels of risk, but about changes in *perceptions of risk*, or at least in reported perceptions of risk. It is a claim about a supposedly widespread loss of confidence in the capacities of medical, scientific and technical progress to solve problems, and about a corresponding growth in reported anxiety and mistrust. These perceptions have currency among populations who in fact live longer and healthier lives than their predecessors enjoyed. Yet the claim about perceptions is accurate. In the UK, for example, MORI public opinion polls confirm that many

[8] Ulrich Beck, *Risk Society*, Sage, 1986; Piotr Sztompka, *Trust: A Sociological Theory*, Cambridge University Press, 1999.

[9] Other writers reject the doom-laden view that new technologies have increased risks. See Aaron Wildavsky, *Searching for Safety*, Transitions: Oxford University Press, 1988; also his 'If Claims of Harm from Technology are False, mostly False or Unproven What Does That Tell Us about Science?', chapter 10 in Peter Berger *et al.*, eds., *Health, Lifestyle and Environment*, Social Affairs Unit. See also John Adams, *Risk*, UCL Press, esp. pp. 179–80, and many of the papers in Julian Morris, ed., *Rethinking Risk and the Precautionary Principle*, Butterworth Heinemann, 2000.

members of the public now claim to distrust numerous groups and professionals to tell the truth about medical, scientific and environmental issues.[10]

UK media accounts of these polls and the public attitudes they sample report that the public do not trust science, industry or politicians. There is also a limited amount of evidence that perceived lack of trust is expressed in action: there are sporadic environmental protests and demonstrations, there is widespread public refusal to buy GM foods and quite a lot of people buy 'alternative' medicines (despite the fact that most have been tested neither for safety nor for efficacy). Yet there is also a great deal of evidence of action that suggests that the public do *not* mistrust scientists, industry or politicians any more than they mistrust others, and that they do not (for the most part) lose trust in entire professions or industries when they become aware of untrustworthy behaviour by a few.[11] Despite some highly publicised professional failures and crimes, there is good evidence that the public continue to place trust not only in doctors, but also in the scientists who develop new medicines, in the industries that produce them and in the regulators who ensure safety standards. Loss of trust, it seems, is often reported by people who continue to place their trust in others; reported perceptions about trust are not mirrored in the ways in which people actually place their trust.

[10] For MORI polls on GMO, see institutional bibliography. Other studies have recorded slightly varying rankings: see L. J. Frewer, C. Howard, D. Heddereley and R. Shepherd, 'What Determines Trust in Information about Food-Related Risks? Underlying Social Constructs', in Ragnar Löfstedt and Lynn Frewer, *Risk and Modern Society*, Earth Scan, 1998, 193–212, see esp. table on p. 198, in which the least trusted information sources, in order, are tabloid newspapers, MPs, ministers, ministries and personal friends(!) and the most trusted are university scientists, medical doctors, consumer organisations, television documentaries and government scientists.

[11] In the UK cases of concern about failures in medical practice are documented in the 2001 Redfern Report on events at Alder Hey hospital and the 1995 Kennedy Report on events at the Bristol Heart Unit. Since the publication of the Redfern Report, the British Medical Association (BMA) has commissioned a poll from MORI, which showed that the public still retains greater trust in doctors than in any other group. See institutional bibliography for all sources, and especially MORI/BMA 2001 on the MORI website.

Claims about mistrust and its practical implications are nevertheless very prominent in public debate. Some influential voices advocate strong and barely coherent interpretations of the famous (if elusive) *precautionary principle*. They suggest, for example, that all and any innovations that may harm the environment should be prohibited, regardless of likely benefits: yet very few changes are guaranteed to have *no* bad effects; even fewer can be guaranteed in advance to be harm-free; and even the status quo (as some of the same voices complain) may have bad effects – so presumably should also not continue.[12] But what does the precautionary principle prescribe when both change and the status quo are judged wrong? There are also many demands for impractical levels of safety and success in medical practice and environmental standards, such as claims that everybody should receive 'the best' treatment: possible only where zero variation of treatment is guaranteed. There are demands that no traces of substances that pollute in large quantities should be permitted in water or food (salt?).[13] There are even occasional demands for a supposed (but literally speaking incoherent) 'right to health', a fantasy that overlooks the fact no human action can secure health for all, so that there can be no human obligation to do so, and hence no right to health. These excessive and unthought-through demands are evidence of a culture in which trust is besieged. Debate is often shrill and hectoring. A culture of blame and accusation is widespread, both in the media and in the literature of campaigning organisations, where fingers are pointed variously at government, at scientists and at business.[14]

[12] For a survey of stronger and weaker interpretations of the principle see Julian Morris, 'Defining the Precautionary Principle' in Julian Morris, ed., *Rethinking Risk and the Precautionary Principle*, Butterworth Heinemann, 2000, 1–21; and Aaron Wildavsky, 'Trial and Error versus Trial without Error', in Morris, ed., 2000, 22–45.

[13] For example the most recent text of the World Medical Association, Declaration of Helsinki benchmarks requirements in medical research by reference to 'best' treatment; see institutional bibliography.

[14] For a useful case study see Parliamentary Office of Science and Technology (POST), *The 'Great GM Food Debate': A Survey of Media Coverage in the First Half of 1999*, 138, May 2000; for suggestive examples see Richard North, 'Science and the Campaigners', *Economic Affairs*, 2000, 27–34.