

AUTONOMY AND TRUST IN BIOETHICS

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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 coined¹ – 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. Hedderley 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.

This looming atmosphere of distrust has arisen amid, and co-habits with, great and well-publicised advances in medicine and the life sciences, in biotechnology and in protection of the environment. Scientific success and reduction of risks to life, health and the environment are manifest not only in research, but also in the application of research to medical practice and environmental protection. Life expectancy has risen and is still rising in the richer world, and also in many (but not all) parts of the poorer world. Medical care has been improving, and many serious health problems are now ones that individuals can address for themselves, for example by stopping smoking or drug use, or by losing weight or exercising more. Even the much criticised – but also much loved – National Health Service (NHS) progresses towards evidence-based medicine. Equally in environmental matters, in the UK and in some other richer countries, air and water are becoming cleaner; greener technologies and energy savings are pursued; agricultural practices that cause environmental harm are being reduced; biodiversity is monitored and the news on biodiversity and wildlife is quite often encouraging.¹⁵ There is even an increasing public recognition that environmental standards matter and must be paid for. In short, reported public trust in science and even in medicine has faltered *despite* successes, *despite* increased efforts to respect persons and their rights, *despite* stronger regulation to protect the environment and *despite* the fact that environmental concerns are taken far more seriously than they were a few years ago.

Taken at face value, the mismatch between increasing advances in safety standards and environmental concern and declining reported trust is strange. Why should trust be declining at a time when reasons for trusting have apparently grown? There could be various good explanations for this surprising fact. For example, some ascribe the current culture of mistrust to the public's lack of scientific education (remedy: improve public understanding of science), and others ascribe it to the poor communication

¹⁵ Tony Gilland, 'Precaution, GM Crops and Farmland Birds', in Julian Morris, ed., *Rethinking Risk and the Precautionary Principle*, Butterworth Heinemann, 2000, 60–83.

skills of doctors and scientists (remedy: teach doctors and scientists to communicate better), or to deeper and persisting conflicts of interest. I shall comment on some of these diagnoses in later chapters. However, I want first to consider the more fundamental difference between perceiving others as trustworthy and actively placing trust.

1.4 JUDGING RELIABILITY AND PLACING TRUST

Loss of trust has become a major issue in public debate, but there has been less discussion of trust and loss of trust in bioethics, or in ethics more generally, than one might have expected. Trust has been a major theme in sociology, but only a minor theme in ethics. In consequence a large amount of discussion of trust focuses on empirical studies of perception of others as trustworthy or untrustworthy, and rather little addresses the practical demands of placing trust. The topics are connected, but they are not the same. The connection is that those who see their world as a ‘risk society’ often find placing trust problematic: but it does not follow that they do not place trust, or even that they place no trust in those whom they claim to think untrustworthy.

Just as total scepticism would produce total paralysis of belief, and is untenable in practice, so total inability to place trust would produce total paralysis of action, and is untenable in practice. In practice we have to take a view and to place our trust in some others for some purposes. Where people perceive others as untrustworthy they may place their trust capriciously and anxiously, veering between trusting qualified doctors and trusting unregulated alternative practitioners, between trusting scientific claims and trusting those of alternative, greenish or counter-cultural campaigners, or modish therapies and diets, between trusting established technologies and medicines and trusting untested or exotic technologies and products. But they do not refuse to trust.

The thought that anyone who sees others as untrustworthy can avoid placing trust is unconvincing. In trusting others to do or refrain from action of a certain sort we do not assume any guarantee

that they will live up to that trust.¹⁶ Trust is not a response to certainty about others' future action. On the contrary, trust is needed precisely when and because we lack certainty about others' future action: it is redundant when action or outcomes are guaranteed. That is why we find it hard, as well as important, to try to place trust reasonably rather than foolishly.

Usually we place trust in others only with respect to a specific range of action, often for action for which they have explicit responsibility. A patient may trust her doctor to act in her best interests in deciding on her treatment, but might not trust him to drive safely. A parent may trust a schoolteacher to teach his child, but not to look after his money or to diagnose an illness. A householder may trust a water company to provide safe tap water, but not to deliver the groceries. However, in other cases trust is unrelated to role. We cannot avoid trusting strangers in many matters, like driving on the correct side of the road or giving what they take to be reliable rather than invented information when asked. And we cannot avoid placing many different sorts of trust in others with whom we have close and complex relationships. In personal relationships trust is often reciprocal and may be given for a very wide range of action.

When we place trust in others, we do not usually trust or even expect them to have our interests entirely at heart, let alone to place our interests ahead of all other concerns. One of the rare, and influential, accounts of the ethics of trust, proposed by Annette Baier, suggests that when we place trust in others we not merely rely on them, but rely on them having at least minimal good will towards us:

Reasonable trust will require good grounds for . . . confidence in another's good will, or at least the absence of grounds for expecting their ill will or indifference.¹⁷

¹⁶ Sztompka, *Trust*; Annette Baier, 'Trust and Antitrust', *Ethics*, 96, 1986, 231–60.

¹⁷ Annette Baier, 'Trust and Antitrust', 235. For a similar view, emphasising the importance of good will for trust see Karen Jones, 'Trust as an Affective Attitude', *Ethics*, 107, 1996, 4–25. For an insightful and in my view more plausible analysis of trust,

But this is often not the case. Our trust in individuals and in institutions, in officials and in professionals, does not (fortunately!) rest on the thought that they have good will towards us. The thought that placing trust requires good will has a context (at most) in personal relationships – and perhaps not in all of those.

We therefore need a broader view of placing trust, that takes account of the fact that we often trust others to play by the rules, achieve required standards, do something properly without the slightest assumption that they have any good will towards us. Sometimes we may know that good will is lacking, and yet trust. A patient may know that a doctor finds him particularly irritating and bears him little good will, and yet trust the doctor to exercise proper professional judgement. Most of us trust the safety of ordinary medicines without knowing much, if anything, about the procedures for safety and efficacy testing to which they have been subjected, or about the companies and regulatory bodies responsible for these procedures, let alone assuming that these companies and regulatory bodies have good will towards us. What is the basis of placing trust when good will does not enter the picture?

It is often thought that we place trust in others because they have proved reliable, and that we withdraw trust from them because they have proved unreliable. Views of others' reliability are useful in placing trust, but they are neither necessary nor sufficient for doing so. In judging that someone is reliable we look to their past performance; in placing trust in them we commit ourselves to relying on their future performance. We can see that knowledge of others' reliability is not necessary for trust by the fact that we can place trust in someone with an indifferent record for reliability, or continue to place trust in others in the face of some past unreliability. Many daily relationships of trust survive a good deal of failure and unreliability; we commonly regard those who withdraw trust after a single lapse (or even after sporadic minor lapses) as excessively suspicious. Proven reliability may be nice, but it is not necessary for placing trust. Equally, we can see that reliability

see Richard Holton 'Deciding to Trust, Coming to Believe', *Australasian Journal of Philosophy*, 72, 1994, 63–76.

is not sufficient for placing trust, both because trust is not directed to natural processes (however reliable) but only to other agents, and because reliable agents are not always trusted.

In judging reliability we draw largely on evidence of past performance; in placing trust we look to the future, and evidence of past conduct is only one of the factors we commonly consider. We expect competent persons to converge in judgements of reliability if they have access to the same evidence; we do not expect the same convergence in placing of trust. If we imagined that placing trust was dictated entirely by another's past record for reliability, we could make no sense of many significant decisions to place trust in others. We could not understand amnesties, or reconciliation, or forgiveness, or confidence building: all are instances of placing trust despite poor evidence of past reliability. Placing trust is not dictated by what has happened: it is given, built and conferred, refused and withdrawn, in ways that often go beyond or fall short of that evidence.

Nevertheless the most common explanation for refusal to place trust is that it is a reasonable response to prior untrustworthiness or unreliability, and correspondingly that trust is a proper response to prior trustworthiness or reliability. For example, distrust of medicine, science and biotechnology is often said to be justified by past action or inaction that has damaged public interests or abused public trust during the last fifty years. Regularly cited examples include the incautious introduction of DDT, the unregulated use of organophosphates; and the building of nuclear power plants without adequate plans for nuclear fuel reprocessing. More recently in the UK mistrust is said to have been caused by poor government handling of the emergence of BSE in cattle, by the one-sided attitude to the introduction of GM crops taken by Monsanto and some others, by worries created by geographically erratic availability of certain forms of medical treatment and by some highly publicised cases of professional malpractice. All of these factors, and many others, may offer some reasons for the public to judge some of those who practise medicine, science and biotechnology unreliable. However those judgements about past

reliability invariably underdetermine their decisions about where to place their trust.

This is not as irrational as it may at first seem. Judgements of reliability are in any case often based on limited and inconclusive evidence. Well-publicised cases of untrustworthy action by professional and office holders offer very incomplete reasons for judging all other professionals or office holders, or even the same ones in a different situation, untrustworthy. In many cases the available evidence is sufficiently porous for agents to find it reasonable either to place or to refuse trust – or to claim to mistrust while in practice placing trust.

If all claims not to trust medicine, science and biotechnology were based on comprehensive evidence of systematic unreliability, past performance would present an extreme challenge to placing further trust. But claims that others are untrustworthy of the sort that are now so common often reflect very incomplete evidence. I shall explore a range of thoughts about sources of claims to mistrust medicine, science and biotechnology. Might it be the case that mistrust sometimes arises even without any knowledge of (significant or widespread) prior failure of reliability, for example because it is too hard to distinguish accurate information from misinformation and disinformation, so too hard to place trust reasonably? Might it sometimes arise from very procedures by which we try to make medical and scientific practice more accountable, and in particular from ways in which we have tried to combine respect for the autonomy of patients and of members of the public with regulatory protection? Or could the very conceptions of autonomy and of respecting autonomy, that have been at the heart of so many policies for regulating medicine, science and biotechnology, threaten the maintenance and creation of trust? Is loss of trust perhaps the price of increasing autonomy? Must we choose between respect for autonomy and relations of trust?

1.5 TRUST AND AUTONOMY IN MEDICAL ETHICS

Answers to all of these questions are complicated because various conceptions of autonomy and of trust are in play, between which

I hope to distinguish. In doing so I shall try to say something about various conceptions of each, and to trace some of their relations to other ideas that are prominent in contemporary bioethics, such as those of respect for persons, informed consent and certain human rights.

I hope to show that some conceptions of autonomy and of trust are compatible, and even mutually supporting. It will not, of course, follow that we must adopt these conceptions of autonomy and of trust. We may find reason to prefer others. However, if we rely on conceptions of autonomy and of trust that cannot be reconciled, then we cannot have both. Correspondingly, if we would like to find a way of enjoying both autonomy and trust we must first find conceptions of each that can be reconciled.

I shall begin the inquiry by posing some intuitive questions about the relation of trust to autonomy within medical ethics, for it is in medical ethics that some of the strongest claims have been made both on behalf of trust and on behalf of autonomy. If we think back into the past, and look to that famous prototype of all professional relationships, the doctor–patient relationship, we have a paradigm of a relationship of trust. The patient approaches the doctor knowing that the doctor is bound as a matter of professional oath and integrity to act in the patient’s best interests, even that the doctor stands at risk of disgrace or disqualification for serious failure in this regard. Although there are always contractual and financial arrangements linking doctor and patient, or doctors and the institutions that organise medical care and employ them, the doctor–patient relationship is supposed to trump any considerations of self-interest and gain. It is a professional relationship that is supposed to be disinterested, long-lasting, intimate and trusting. The image in the frontispiece of this book can be seen as depicting a trusting, traditional doctor–patient relationship, one-to-one, indeed face-to-face, set in the confidential confines of a professional office.

This traditional model of the trusting doctor–patient relationship has been subject to multiple criticisms for many years. Traditional doctor–patient relationships, it has been said on countless occasions, have in fact nearly always been based on asymmetric

knowledge and power. They institutionalise opportunities for abuse of trust. Doctor–patient relationships were viewed as relationships of trust only because a paternalistic view of medicine was assumed, in which the dependence of patients on professionals was generally accepted. The traditional doctor–patient relationship, so its critics claim, may have been one of trust, but not of reasonable trust. Rather, they claimed, patients who placed trust in their doctors were like children who initially must trust their parents blindly. Such trust was based largely on the lack of any alternative, and on inability to discriminate between well-placed and misplaced trust.

If there was one point of agreement about necessary change in the early years of contemporary medical ethics, it was that this traditional, paternalistic conception of the doctor–patient relationship was defective, and could not provide an adequate context for reasonable trust. A more adequate basis for trust required patients who were on a more equal footing with professionals, and this meant that they would have to be better informed and less dependent. The older assumption that relations of trust are in themselves enough to safeguard a weaker, dependent party was increasingly dismissed as naive. The only trust that is well placed is given by those who understand what is proposed, and who are in a position to refuse or choose in the light of that understanding. We can look at the same image with a less innocent eye, and see it as raising all these questions about the traditional doctor–patient relationship. In this second way of seeing the picture the doctor dominates: the white coat and intimidating office are symbols of her professional authority; the patient’s anxious and discontented expression reveals how little this is a relationship of trust.

These considerations lie behind many discussions of supposedly better models of the doctor–patient relationship, in which patients are thought of as equal partners in their treatment, in which treatment is given only with the informed consent of patients, in which patient satisfaction is an important indicator of professional adequacy, in which patients are variously seen as consumers, as informed adults and are not infantilised or treated paternalistically

and in which the power of doctors is curbed.¹⁸ In this more sophisticated approach to trust, autonomy is seen as a precondition of genuine trust. Here, as one writer puts it, ‘informed consent is the modern clinical ritual of trust’,¹⁹ a ritual of trust that embeds it in properly institutionalised respect for patient autonomy. So we can also read the image in the frontispiece in a third, more optimistic, way as combining patient autonomy with mutual trust in the new, recommended, respecting way. What we now see is a relationship between equals: the patient too is a professional, dressed in a suit and sitting like an equal at the desk; the patient has heard a full explanation and is being offered a consent form; he is deciding whether to give his fully informed consent. Trust is properly combined with patient autonomy.

This revised model of doctor–patient interaction demands more than a simple change of attitude on the part of doctors, or of patients. It also requires huge changes in the terms and conditions of medical practice and ways of ensuring that treatment is given only where patients have consented. Informed consent has not always been so central to doctor–patient relationships, which were traditionally grounded in doctors’ duties not to harm and to benefit. Informed consent came to be seen as increasingly important in part because of legal developments, especially in the USA, and in part because of its significance for research on human subjects, and the dire abuse of research subjects by Nazi doctors. The first principle of the Nuremberg Doctors’ Code of 1947 states emphatically that subjects’ consent must be ‘voluntary, competent, informed and comprehensive’.²⁰ Only later did the thought emerge clearly that consent was also central to clinical practice, and that patient autonomy or self-determination should not be subordinated to doctors’

¹⁸ R.A. Hope and K.W.M. Fulford, ‘Medical Education: Patients, Principles, Practice Skills’, in R. Gillon, ed., *Principles of Health Care Ethics*, John Wiley & Sons, 1993.

¹⁹ Wolpe, ‘The Triumph of Autonomy’, 48.

²⁰ See Faden and Beauchamp, *A History and Theory of Informed Consent*; Ulrich Tröhler and Stella Reiter-Theil, *Ethics Codes in Medicine: Foundations and Achievements of Codification Since 1947*, Ashgate; Lori B. Andrews, ‘Informed Consent Statutes and the Decision-Making Process’, *Journal of Legal Medicine*, 30, 163–217; World Medical Association, Declaration of Helsinki, 2000; see institutional bibliography.

commitments to act for their patients' benefit or best interest. Yet despite the enormous stress laid on individual autonomy and patient rights in recent years, this heightened concern for patient autonomy does not extend throughout medicine: public health, and the treatment of those unable to consent are major domains of medical practice that cannot easily be subjected to requirements of respecting autonomy and securing informed consent.²¹

From the patient's point of view, however, the most evident change in medical practice of recent decades may be loss of a context of trust rather than any growth of autonomy. He or she now faces not a known and trusted face, but teams of professionals who are neither names nor faces, but as the title of one book aptly put it, *strangers at the bedside*.²² These strangers have access to large amounts of information that patients give them in confidence. Yet to their patients they remain strangers – powerful strangers. They are the functionaries of medical institutions whose structures are opaque to most patients, although supposedly designed to secure their best interest, to preserve confidentiality and to respect privacy. Seen 'from the patient's point of view every development in the post World War II period distanced the physician and the hospital from the patient, disrupting social connection and severing the bonds of trust'.²³

From the practitioner's point of view, too, the situation has losses as well as gains. The simplicities of the Hippocratic oath and of other older professional codes have been replaced by far more complex professional codes, by more formal certification of competence to perform specific medical interventions, by enormous increases in requirements for keeping records and by many exacting forms of professional accountability.²⁴ In medicine, as in most

²¹ See chapter 2. The marginalisation of these topics may reflect their poor fit with the popular ideal of patient autonomy.

²² David J. Rothman, *Strangers at the Bedside: A History of How Law and Ethics Transformed Medical Decision-Making*, Basic Books, 1991. Rosamond Rhodes and James J. Strain, 'Trust and Transforming Healthcare Institutions', *Cambridge Journal of Healthcare Ethics*, 9, 2000, 205–17.

²³ Rothman, *Strangers at the Bedside*.

²⁴ Nigel G.E. Harris 'Professional Codes and Kantian Duties', in Ruth Chadwick, ed., *Ethics and the Professions*, Amesbury, 104–15. See chapter 6 below.