

## 8 DNA and ethics

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We are not short of public discussion of ethical issues arising from genetic knowledge. Enthusiasts and scaremongers fill the columns and the airwaves with their hopes and fears about 'designer babies', GM crops, pharmacogenetics and a future in which everyone carries a genetic smart card. Each of these possibilities, like any other complicated change, would raise ethical issues. The hardest ethical issues that we currently face, however, are rather different. Many have to do with the use and control of genetic information. Is genetic information exceptional? Are there good reasons to control access to it more tightly than we control access to other sorts of personal or medical information? Does genetic information 'belong' to individuals or to families? Could there be a 'right to know' the results of DNA tests taken by relatives, or a 'right not to know' – or both? *How* informed do we have to be to give informed consent to genetic tests?

### Enthusiasts and scaremongers

Few public debates are more polarised than those about new genetic technologies. Yet the enthusiasts and the scaremongers agree on one point. Both take it that the most serious ethical problems cluster around possible, or likely, modifications of living organisms by new genetic technologies. Of course, they disagree radically in their assessments of the opportunities and risks that these technologies present, and about what we should and should not do.

Enthusiasts think that the use of technologies for genetic modification will generally prove liberating and beneficial, especially for human beings: we are

entering a brave new world. Medicine, in particular reproductive medicine, will be transformed: we shall cure illness with genetic therapies and research in pharmacogenetics will lead to better targeting of medicines. We shall have genetically 'enhanced' children, with chosen and desirable traits. Agriculture will be transformed by genetically modified plants and animals, which will go far to solve the problem of world hunger, reduce use of pesticides, provide medicines and save the environment.

Scaremongers think that using technologies for genetic modification will harm and destroy human and other organisms, and their environment: they point to doomsday scenarios. They warn us that genetically modified organisms – bacteria or plants, animals or humans – might have unforeseen defects, that they might proliferate or hybridise, create unforeseen plagues or environmental damage, and might divide human societies into a permanently privileged group of the 'genetically enhanced' and a 'genetic underclass'.

These disagreements colour views on public policy. Enthusiasts often take a libertarian stance. For example, John Harris of the University of Manchester has argued for extensive reproductive *autonomy*, including a supposed 'right to reproduce with the genes we choose and to which we have legitimate access... in ways that express our reproductive choices and our vision for the sorts of people we think it right to create'.<sup>1</sup> Scaremongers often take a prohibitionist stance. For example, the Greenpeace briefing on GM crops opposes the release of all and any GM organisms into the environment.<sup>2</sup> Enthusiasts and scaremongers share a tendency to sensationalise, to glamorise or to demonise, genetic technologies, rather than to judge applications in the light of evidence. It is hardly surprising that they are both drawn to quite extreme ethical positions.

At the risk of being much more boring, I want to discuss some ways in which ethical questions raised by uses of genetic technologies are more ordinary, more diverse, and demand more detailed consideration of specific applications and their likely effects than some enthusiasts or scaremongers think necessary. I shall start with technologies for genetic modification of human and other organisms, and will then turn to technologies for using genetic information.

<sup>1</sup> John Harris, 'Rights and reproductive choice', in John Harris and Søren Holm (eds.), *The Future of Human Reproduction: Ethics, Choice and Regulation*, Oxford: Clarendon Press, 1998, pp. 5–37; p. 34.

<sup>2</sup> *Genetic Pollution – a Multiplying Nightmare*, Greenpeace, February 2002.

### **Genetic modification: human health and reproduction**

Consider for a moment where we *actually* stand in the application technologies for genetic modification to human beings, and in particular what gene therapy and a range of reprobgenetic technologies currently offer.

Gene therapy is still at a very early stage – although there are many non-genetic medical interventions for managing, and some for preventing, genetic diseases. Haemophilia can be managed; the retardation to which Phenylketonuria (PKU) can lead can be prevented. Still, cure is better than treatment, and this is what gene therapies might provide. However, at present (with few exceptions) gene therapy is at the stage of research or clinical trials. These trials are closely controlled by the Gene Therapy Advisory Committee (GTAC) in the UK (and by parallel bodies overseas); in the UK germ line gene therapy, where modifications would be transferred to future generations, is prohibited. If and when reliable gene therapies are developed, patients may not find them very different from more ordinary medical interventions.

Reprobgenetics at present also offers pretty limited new possibilities: yet discussion of the possibility of having genetically 'enhanced' children ('designer babies') gallops ahead of reality. At present genetic technologies are just not very useful if you want to design a baby. Couples who know that they risk having children with an identifiable single gene disorder – say, cystic fibrosis or Tay Sachs disease – can now choose not to do so, either by using in-vitro fertilisation (IVF) with preimplantation diagnosis (very rare), or by post-conception genetic testing and abortion if the foetus is affected (less rare). In the past such couples had fewer options: they had to choose between childlessness and adoption, or risk having an affected child. Using the new technologies to avoid having a child with a specific, anticipated and very damaging genetic variation is a far cry from designing a child. The reprobgenetic technologies in *actual* use extend but do not revolutionise parental choice, and the ethical problems they raise are hard but familiar.

Similarly with technologies for *sex selection*. Sex selection can be done (to a degree) using genetic and other new technologies, and is strictly regulated in the UK. Advocates of more liberal access to new technologies for sex selection see it as important for reproductive choice; opponents point to the unintended consequences, typically a large excess of men (not of women). These unintended consequences have arisen, particularly in India and China, where sex selection is routinely secured on a massive scale by traditional methods such as neglect,

abandonment and infanticide of little girls, and (more recently) by amniocentesis and selective termination. Some technologies may be new, but the issues are not.

This brings me back to *designer babies*. There are at present *no* genetic technologies for choosing most of the characteristics that parents prize, such as intelligence or a happy disposition. To the best of our knowledge there are genes that contribute to the likelihood of developing these and many other desirable (and undesirable) traits, but no single gene is decisive. If single genes were decisive, we would probably have discovered their pattern of inheritance long since, as we did for single gene diseases such as Huntington's, cystic fibrosis or haemophilia. Since we do not yet know much about the genetics of polygenic traits, about interactions between susceptibility genes, or about gene–environment interactions, we do not yet know what would have to be done to design children with these prized human characteristics.

If we do gain that knowledge, designing parents would face the risks and rigours of IVF combined with complex genetic modification (as opposed to embryo selection). At present we are many steps away from the designer baby scenario, lacking adequate knowledge of susceptibility genes or their interactions, and lacking acceptable and reliable techniques for complex genetic modification of human embryos. For the time being, and I take it for a good time to come, a good education and a cheerful home remain the best bet for those who want an intelligent, happy child. What is on offer is simply less promising, or less threatening, than many discussions suggest, and we can do no more than ensure that we maintain robust ways of controlling the application of any further reprobogenetic technologies.

#### **Genetic modification: micro-organisms, plants and animals**

Enthusiasts and scaremongers focus on present as well as possible future scenarios when they discuss technologies for the genetic modification of micro-organisms, plants and non-human animals. These technologies are neither as alien nor as novel as some scaremongers often suggest, nor as transformative as some enthusiasts hope. Genetic modification is not a recent or unheralded innovation. It is the engine of evolution and the basis for traditional and not-so-traditional plant and animal breeding. Perhaps the most appropriate way to judge the acceptability of uses of GM technologies is to compare them with earlier forms of genetic modification.

Let me start with micro-organisms. Many have a talent for genetic modification. Bacteria achieve antibiotic resistance by picking up novel DNA from other bacteria; the influenza virus changes itself so readily that it makes vaccines obsolete, and causes significant human illness and mortality. Technologies for genetic modification have been applied to micro-organisms since the 1970s. Many modifications have been permitted, and proved valuable. Most vitamins, antibiotics and amino acids are produced in genetically modified bacteria. Genetically modified bacteria are used in making 85% of the cheese eaten in the UK, in place of rennet, taken from the stomachs of calves – a change that is advantageous to vegetarians, as well as to calves. Micro-organisms modified to produce human insulin and human growth hormone are routinely used and have produced considerable health and safety benefits. Other genetic modifications of micro-organisms might prove useless or dangerous. Modified bacteria and viruses *could* be used to spread human and animal disease, as recurrent worries about bio-terrorism remind us. Given the real benefits and possible harms produced by modified and unmodified micro-organisms, the only reasonable approach is to maintain systems for detailed, effective regulation backed by powers to prohibit research and use of modified micro-organisms whenever there are reasons to do so.

Similar things might be said about the genetic modification of plants, which is the scene of so much controversy in the UK and the EU. Genetic modification of plants takes place entirely naturally, and not always to the benefit of human and animal life: the world is full of successful plants that achieved genetic modifications that made them taste nasty and have toxic effects on various animals and insects. The world is also full of plants that hybridise promiscuously, sometimes with mildly undesirable results: the wheat and tares of the Bible are *both* of them genetically modified plants. The wheat was produced by human manipulation, by the action of generations of Stone Age men and women, and has provided the staff of life for countless millions. The tares were a back-cross between domesticated wheat and its own wild ancestor, einkorn wheat. Tares are a problem for farmers – but not a catastrophe.

So the wholly unspecific question 'Are genetically modified plants a good or a bad thing?' is unlikely to have a sensible answer. Specific modifications of particular plants may very well turn out to be beneficial or harmful in various ways for various species, or neither (traditional plant breeders find that few of the genetic modifications they produce are of the slightest value). Whether a

modification is harmful or valuable seems to me independent of the way it was produced. Modifications produced either by traditional technologies or in the laboratory *might* be useful, useless or harmful. The sheer variety of possible outcomes is a good reason to regulate research on genetically modified plants, release into the environment, and agricultural use with care and rigour in the light of evidence – and good reason to apply equally tough standards to traditional plant breeding and the importation of exotic plants.

Prohibitionists think a selective, evidence-based approach to GM plants inadequate. Some suggest that the so-called ‘Precautionary Principle’ offers a conclusive reason for prohibiting *all* laboratory-based genetic modification of plants. There are many formulations of this principle, and some of them do not offer a plausible or useful guide to action. When the Precautionary Principle is seen as a requirement to take care, to be prudent and cautious, it is very plausible. An injunction to be prudent is not precise, or thrilling; but it is ethically important. Adequate regulation of genetic technologies has surely to be based *in part* on a commonsense interpretation of the Precautionary Principle, that takes serious account of evidence and is combined with due attention to other ethically important considerations. How else could anyone judge which acts are cautious, rash or neither?

However, prohibitionists do not think commonsense interpretations of the Precautionary Principle adequate. They recommend supposedly stronger versions, which (they claim) provide reasons for avoiding all GM technologies, indeed all new technologies, that *might* have bad consequences. The stronger versions of the principles are now sometimes formulated (in spurious homage to scientific method) by saying that we must take account of so-called ‘unknown unknowns’, or in more politicised versions by a general claim that we should avoid ‘possible risks’ or ‘shift the burden of proof to those who create risk’.<sup>3</sup> Unfortunately, far from providing a knock-down argument against any planting of GM crops, or against using other new genetic technologies, these versions of the Precautionary Principle cannot help anyone to decide which technologies to use and which to shun.

I believe that the intellectual credibility of the Green movement has been weakened by its enduring love-affair with supposedly strong versions of the Precautionary Principle. Their fatal attraction is an illusory strength, tempting

<sup>3</sup> John Humphries, *The Great Food Gamble*, London: Hodder and Stoughton, 2002, p. 109.

because it suggests a way of bypassing the chore of assembling and assessing the evidence for and against proposed courses of action. The strong formulations of the principle seem attractive because they can be cited as reason to reject *any* GM crop, since it *might* have some bad effects. Yet the same versions of the principle also torpedo all the innovations that Greens advocate (exclusive reliance on biological control of pests and banning artificial fertilisers *might* have bad effects). They also undermine staying with the status quo: there is little doubt that intensive farming *actually* has various bad (as well as beneficial) effects. Serious arguments for and against GM crops, like serious arguments for or against organic farming, or for or against intensive agriculture, must take account of the evidence for or against *specific uses of specific technologies*. A claim that we should avoid all possible risks or 'shift the burden of proof to those who create risk' cuts no ice unless we can identify some line of action that creates zero risk. Since we cannot do that, we need to consider *which* technologies would create *which* risks, and which risks are *more* and which *less* tolerable; but we cannot do this without taking a rigorously evidence-based view of specific uses of specific technologies.

I suspect that most Greens have rather less faith in the Precautionary Principle than some proclaim. If they *really* thought that they had a knock-down argument against new technologies, including GM technologies, they would view all appeals either to evidence or to other ethical principles as redundant, and do without them. Yet they in fact constantly appeal to selective evidence, for example to the benefits of compost, or of biological pest control; and they often appeal to other ethical principles, such as the importance of limiting human and animal suffering and (various, supposed) human rights and benefits. More startlingly, they quite often appeal to a libertarian principle of consumer choice: this principle is supposed to underpin a requirement to label GM products. Those who invoke it may find that it boomerangs, since it suggests that consumers have a right not only to know which products contain GM ingredients, but also to have such products on offer.

Since the supposedly strong versions of the Precautionary Principle succumb to this *reductio ad absurdum*, we can gain more from the weaker versions. These we have reason to take entirely seriously in working out *which* uses of *which* technologies for genetic modification there is reason to ban or to permit, under *which* conditions and for *which* purposes. The devil, inevitably, is in the detail.

The problem is to combine prudence and caution with other ethical concerns, such as limiting human and animal suffering, improving food security for the poor, securing greater justice and benefiting health and welfare. Those who take the trouble to think through the details may or may not reach what are currently seen as Green-ish conclusions. Full consideration of the ethical issues and of the evidence *might* endorse organic farming plus severe restriction or prohibition of GM. Alternatively it *might* endorse a combination of Green-ish and high-tech approaches – for example organic farming with GM crops; or it *might* point in other directions.

Similar considerations are relevant to genetic modification of animals. There is no doubt that some genetic modification of animals, produced by traditional as well as by new methods, may cause harm and suffering. Think how much animal suffering the zealous breeders of dogs with a ‘slinky’ look (and hip dysplasia) or squashed faces (and breathing problems) have caused. They failed to think about the whole animal, and bred for isolated ‘features’ or ‘points’. Other genetic modifications – whether achieved by traditional or by newer techniques – may benefit not only the species modified, but also other animals (including humans) or the environment. For example, genetic modification of sheep *may* eliminate susceptibility to scrapie, presumably with benefit to sheep, and to other animals, including humans. Genetic modifications of pigs *may* reduce their excretion of methane and thereby their contribution to greenhouse gases, so benefiting the environment. The assessment of these possibilities does not depend on whether modifications arise naturally, are produced by selective breeding or are the result of genetic modification in the laboratory.

Once again the strong versions of the Precautionary Principle cut no ice. A commonsense version, recommending caution in all we do, is well taken; but caution is illusory unless it is evidence-based, and is only one of many ethical considerations relevant to the complex decisions that farmers and breeders, scientists and policy-makers, and the public at large have to make. The exorbitant versions of the Precautionary Principle that prohibit action unless it is *guaranteed* to have no bad effects can only paralyse. We can be cautious, we can even choose to ‘err on the side of caution’; but this requires rigorous consideration of cases and evidence-based assessment of new and traditional technologies. Prudence and caution are undermined rather than brought to perfection unless we take evidence seriously.

### Genetic information: identity and sense of identity

So far I have argued that technologies for genetic modification are often less dramatic and less strange than enthusiasts and scaremongers suppose, and that the ethical problems they raise are more similar to those raised by traditional technologies than they assume. We live in a world in which genetic therapies and genetic modifications have to be evaluated and used with rigour and care, in the light of relevant evidence. There is no *single* or *simple* principle for deciding which technologies to prohibit, or what conditions to set on those not prohibited. There is no way to avoid the hard work of assessing possibilities and cases as carefully as we can, in the light of available evidence and of robust rather than gestural ethical arguments.

Readers may by now suspect that a discussion of Ethics *and DNA* is redundant. Yet a look at genetic technologies that are *not* used to modify organisms shows that some of them give rise to quite distinctive ethical problems. The genetic technologies to which I shall now turn are technologies that deploy *genetic information that pertains to individuals*. These technologies have already been put to many uses.

Genetic information – mainly DNA information – obtained from individuals is used for many medical purposes other than gene therapy and genetic modification. It can play a role in diagnosis and in treatment, and can inform reproductive decisions. If pharmacogenetics develops, it will be used routinely in prescribing medicines. Genetic information obtained from individuals can also be linked to other information about the same or about distinct individuals. Technologies for handling and linking DNA information are already in daily use by the police, the immigration service, the child support agency, family historians, archaeologists, stockbreeders and many others, and are important for public health and health research.

Genetic information that pertains to individuals is widely seen – not only by enthusiasts and scaremongers – as distinctive, personal and peculiarly sensitive, even as vital to our very identity. The phrase 'genetic identity' has acquired a wide currency, and has migrated from academic to popular discourse. A typical example in the *Independent* in September 2000<sup>4</sup> quotes a man conceived by donor insemination as saying that not knowing anything about his biological father leaves him feeling that he is 'missing 50% of my genetic identity'.

<sup>4</sup> Marie Woolf, 'New Rights for Children of Sperm Donors', *Independent*, 19 September 2000.

The term 'genetic identity' sounds as if it refers to something important, even foreboding; yet its current uses often refer to, and confuse, a number of quite distinct matters.

On a first, metaphysical, understanding of the notion of *genetic identity*, genetic makeup is viewed as the basis of personal identity, as that which makes people distinct from one another and reveals what is fundamental about them. This conception of genetic identity is criticised by some academic writers as implying some form of *genetic essentialism*, but is quite often endorsed in more popular (indeed populist) writing on genetics, as exemplified by the catchphrase 'genes are us'.

The claim that genes are the basis of the identity of persons is clearly false. Genetic makeup is not sufficient to individuate a person: identical twins who share their genetic makeup are distinct persons. They differ in many other characteristics, initially in gestational history and time of birth, thereafter in countless other properties. The fact that genetic difference would *generally* be sufficient to distinguish one individual from another is irrelevant. Precise time of birth is *generally* sufficient to distinguish one individual from another; but we know that 'birth time identity' is not always sufficient to individuate persons.

On another, cultural, interpretation of the notion, *genetic identity* does not mean that individuals are *distinct*, but rather that they *share* something. During the last two decades phrases like 'ethnic identity' or 'religious identity' have been used not to pick out *distinct* individuals, but to pick what individuals *perceive* or *represent* themselves as *sharing* with others. Knowing a person's social, national or religious identity – or (as we used more accurately to say) their *sense of identity* – amounts to knowing what they share with certain others. If my ethnic identity is Cornish or Kurdish this will show whom I view as fellow countryman and whom as outsider; if my religious identity is Coptic or Catholic this will show whom I view as fellow communicant and whom as heretic, or at least religiously misguided. *Senses of identity* are not generally matters of discovery, but rather of known identification, commitment and aspiration; they are clusters of shared beliefs, aspirations and ideals. I suspect that the person who felt that ignorance of his father damaged his 'genetic identity' meant that he lacked knowledge of things that he shared with his father and his paternal lineage.

Yet I do not think that the knowledge he craved is best described as knowledge of his *genetic identity*. What he sought was knowledge about his family

tree, that is knowledge of lineage and origins, and would be better thought of as knowledge of *genealogical identity*, or more prosaically as *genealogical information*. Gaining this knowledge would not yield much (if anything) in the way of knowledge of specific genetic variations that he shared with his paternal lineage. It would tell him *that* he shares genes with certain others, but not *which* genes he shares. This may not matter much, given that beliefs about one's genetic makeup are not (usually) important to anyone's sense of identity. Most of us have minimal beliefs about or commitments to our genetic profile or its implications, but this does not weaken our sense(s) of identity. The term 'genetic identity' misleads because it suggests that genealogical information will of *itself* enrich, enlarge or contribute to a person's sense(s) of identity. In fortunate cases those who gain new genealogical information may identify with previously unknown relatives, with whom they come to share certain beliefs or aspirations: their sense(s) of identity may converge with those of their newly identified relatives. In other cases there will be no happy convergence of sense of identity.

#### Personal genetic information: sharing and anonymity

If genetic information that pertains to individuals is *neither* the basis of personal identity *nor* the basis of sense(s) of identity, is it of any particular ethical importance? Should it be treated differently from other personal information? Is it any more sensitive than the personal information found on drivers' licences and passports?

Those who believe that genetic information is exceptional often suggest that this is because it is *familial* rather than (solely or strictly) *individual*. It is true enough that genetic information is familial. But what follows? Many other sorts of personal information are familial, such as information about family fortunes or family jokes. And even if some familial information is sensitive and something we seek to keep private, not all of it is. Families may not want information about their quarrels and their debts to be public, but may hope that information about their achievements and distinctions is public. Indeed, some familial information is unavoidably public: it is hard to hide prominent family traits like baldness or the Habsburg nose.

So a *general* claim that genetic information *is* exceptional or peculiarly sensitive simply because it is familial seems ill founded. Nevertheless certain *uses*

of genetic information, and in particular of DNA information, may raise distinctive ethical problems. I believe that these problems cluster where the information is not obvious (so not unavoidably public), yet pertains to more than one individual. In discovering such information about ourselves we may also discover something nonobvious about our relatives, possibly something that they do not know about themselves. These small facts give rise to ethical quandaries because they challenge current individualistic conceptions of personal information, personal privacy and informed consent.

The most obvious cases arise where individuals have DNA tests in the course of medical treatment or for reproductive purposes. What makes the test results sensitive is their nonobvious medical and reproductive implications; what makes them distinctive is that (unlike most such information) they also pertain to relatives. For example, a person whose grandparent died of Huntington's disease and whose parent refused tests may choose to be tested and discover that he or she has inherited the gene, so will suffer the disease, and thereby discovers that the parent who refused testing unknowingly has the same prospects (matters are quite definite here, as in few other cases, because the Huntington's gene is dominant and highly penetrant). More typically, people whose DNA test results reveal genetic risks can infer that certain relatives are also at risk. They obtain sensitive and difficult information about their relatives. Disclosure to those relatives might prompt radical changes in reproductive decisions and life plans; nondisclosure is equally morally problematic.

The ethical puzzles that arise are most easily stated for the case of identical twins. In seeking DNA information about myself – information that is presumed on a standard, individualistic view to be mine to seek – I discover information that is as true of my identical twin as of me. Does it follow that my twin had a right to insist that I seek prior consent, or that my twin's refusal would have limited my right to seek such information about myself? And once I obtain DNA information about myself, does my twin have a right to share the knowledge? Or, alternatively, a right not to share it? What practical content and what arguments could be given for any of these supposed rights? If DNA tests required consent from (all possibly at-risk members of) families, would individuals have to do without tests, even if medically important, whenever one or another relative refuses consent? And what is to be done where relatives cannot be contacted or disagree? Is there a right to 'genetic privacy', and what does it cover? Do relatives have rights that limit one another's rights to privacy?

As you can see, these issues are often discussed in terms of appeals to supposed rights. I suspect that this proliferation of problematic and unargued rights claims means that we have spotted some interesting questions, but remain pretty much in the dark about answers. In general we do not gain much clarity about rights claims until we can formulate the counterpart claims about duties, and in this area we have hardly begun. Just listing some of the duties that would correspond to these supposed rights is revealing. If relatives-at-risk have a *right to know* DNA information obtained by an individual, then that individual has a *duty to share* the information obtained, hence only a restricted *right to personal privacy*. On the other hand, if relatives-at-risk have a *right not to know*, then an individual who learns difficult or upsetting DNA test results has a *duty not to share* this information, unless the relatives waive their rights. Yet how could relatives-at-risk who do not know what has been discovered waive either a *right to know* or a *right not to know*? And if relatives-at-risk have both a *right to know* and a *right not to know* genetic information that pertains to them, from individuals who obtain it, then that individual would have both a *duty to share* and a *duty not to share* the same information with the same relatives-at-risk. Unrestricted versions of the two rights evidently conflict; but which restrictions are convincing?

These puzzles suggest that we have barely begun to articulate the challenges that certain uses of genetic (and perhaps other) information pose to individualistic conceptions of personal information, privacy and informed consent. Nor are matters made easier if we abandon the vocabulary of rights and try to articulate the issues in terms of informed consent requirements. In the first place, such requirements are themselves often supposedly justified by reference to rights (questionable conceptions of individual autonomy sometimes playing a mediating role). Secondly, informed consent requirements prohibit acting on others in ways to which they have not freely consented on the basis of (full) information. Thirdly, they prohibit use or disclosure of personal information about others except where those others have freely consented to use or disclosure. Yet we often permit individuals to use and disclose information about others without their consent. For example, the hallowed medical practice of taking a family history invites patients to disclose information about the health of relatives *without their consent*.

Is the project of classifying information exclusively and exhaustively *either* as personal to individuals (so subject to informed consent requirements) *or* as

public (so not subject to such requirements) perhaps misguided? Or are these puzzles raised by familial DNA and health information atypical? Perhaps such cases are confined to clinical genetics and reproductive medicine, where account can be taken of the problems created by information that is accessible to individuals yet does not pertain solely to individuals. Perhaps other uses of DNA information are just less problematic. After all, in many cases there is no need to establish *any* of the medically or reproductively sensitive implications of a person's DNA. For example, when DNA information is used for forensic purposes, samples are simply matched and their health and familial implications need not be established, communicated to the affected individuals, or disclosed to relatives, let alone made public.

Matching DNA information is perhaps just like matching other sorts of evidence. This was certainly suggested by the title of a 1999 Home Office consultation, which linked the rather surprising trio of topics 'Footprints, fingerprints and DNA samples'. All three types of information are forensically important, because samples from different sources can be matched. By itself, a discovery that two DNA samples – or for that matter two footprints – match cannot identify a person. The discovery of matching samples of DNA is, however, reliable evidence that one and the same individual (or, of course, his or her identical twin!) was the source of both samples. Given other information, a DNA match may show that a single individual was present at two scenes of crime, and ultimately provide a basis for arrest and conviction. Equally, given other information, the lack of a DNA match can eliminate suspects or suggest that distinct individuals were present at two scenes of crime. Matched DNA samples do not by themselves identify persons – let alone prove whodunit. Once linked to other information, however, they are of high evidential value. Footprint evidence is rather less useful: a match may lead one to someone else with the same shoes, and is useless if shoes are thrown away. Even matching fingerprints may be smudged, and *in extremis* skin grafts can undermine their evidential value. By contrast, the evidence provided by DNA samples retains its value through and far beyond individual lives.

In forensic uses of DNA matching, issues about the sensitivity of genetic information apparently vanish because (in general) nothing sensitive is determined or revealed. The police have no interest in – and no budget for – finding out whether a suspect carries a gene for sickle cell disease or for familial forms of breast cancer. They do not seek out or interpret the medical information that

is latent in the DNA samples that they match. They use the information to get their man or woman – and to eliminate irrelevant suspects. The ethical issues that arise in the use of DNA samples for forensic purposes are therefore quite different from those that arise in considering GM technologies: they centre on the use of state power to request and retain samples, and on the dangers of contaminated evidence and of unauthorised uses of a forensic database. They have nothing, however, to do with the sensitivity of information about health or family prospects, or (excepting the identical twins) with the fact that genetic information is not strictly individual.

Nevertheless, other uses of technologies for matching DNA samples raise questions that are as sensitive as those that arise in medical and reproductive contexts. The matching techniques that are used to determine whether samples come from a *single* individual can also be used to determine whether they come from *related* individuals. Genetic profiles can be used to settle paternity or nonpaternity, to link lost children to their relatives, to test the kinship claims of would-be immigrants and would-be inheritors, and to establish kinship with unidentified human remains. DNA matching may raise or resolve claims in some of the most fraught and distressing situations that we can imagine, many of them familial situations. These typical uses of DNA matching raise both the questions about authorisation and proper use that arise in forensic uses, and those about the limits of individual and familial claims that arise in medical and reproductive contexts. Once again, it is because matching is with putative relatives, because DNA information is not solely individual, that ethical problems arise. Once again, a view that informed consent by an individual legitimates DNA matching is placed under great pressure. Indeed, DNA matching can be undertaken without consent from those most affected, or from their relatives: third parties have only to lay hands on a hair or tissue and a website, and to pay the fee.

The difficulties may lie even deeper. The deeper problems may be not that there is a mismatch between an individualistic conception of informed consent and the reality that DNA information is familial. It may be that the underlying assumption that information is always private to individuals of whom it is true should be questioned. I have already noted that we regard a great deal of obvious information that has a genetic basis – e.g. hair colour and eye colour – as routinely and unavoidably public. But when and why is nonobvious information to be seen as private to those of whom it is true? We cannot answer

this question by appealing to an unargued notion of 'genetic privacy': the point is to determine what is and what is not private.

The importance of thinking through these elementary issues is becoming more urgent with the establishment of databases that link DNA with other types of information about individuals, such as information about health, medical treatment or lifestyle, and even genealogical information. Such databases – the DeCode project in Iceland, prospectively BioBank in the UK – are seen as important for health research. Is the storage, processing and use of data acceptable provided that those to whom the information pertains have given their informed consent? Is consent adequately informed if it conforms to data protection requirements?

Here I think we may feel pretty uneasy. Data protection legislation takes no account of the possibility that some information may not in the first place pertain just to individuals. In fact, it takes a more radically individualistic view of personal data and informed consent than has been traditional in medical practice, or elsewhere. In the past, health research was deemed ethically acceptable provided that adequate anonymisation prevented unauthorised identification of individual patients beyond the circles of those responsible for their treatment. Current standards of data protection demand more. They demand *either* that all information that pertains to individuals be irreversibly anonymised (which precludes data linkage) *or* that those who use or link the data seek informed consent from the individuals to whom it pertains for the specific uses to which the data are put.

This has created a crisis for any retrospective use of medical information, or DNA information, for health research that was not (and often could not be) anticipated when the information was first collected. If prior consent from data subjects were required, information on former patients could never be used in investigating new diseases. It is a fantasy to imagine that prior consent can be given to future research projects.

Indeed, it is unclear whether *any* ethically convincing form of informed consent to highly complex uses of DNA information is possible. Individuals may reasonably feel that their capacities to grasp information and to give or refuse informed consent are simply overwhelmed if they are asked to consent to inclusion of very complex information in massive data sets linked in complex ways with other complex data. Yet if data linkage without specific consent from data subjects is unacceptable, and data linkage with their consent is

unattainable, how are we to maintain public health records and how can we conduct health research? More generally, how can we make use of knowledge gained from treating one patient in treating others? Given that all patients are treated on the basis of medical knowledge of previous patients, can it make sense to subject all use of information about any individual patient to his or her consent? Or might we have reason to reconsider data protection requirements and revert to the view that anonymisation – including reversible anonymisation – is adequate protection of individual privacy? How might we take better account of the fact that some information is not solely individual, of the reality that capacities to understand information are limited, and of the reality that health policy has to draw on information that pertains to individuals even when explicit consent cannot be obtained? These are large and topical questions which need a lot of attention. They are good reasons for looking beyond current battles about genetic modification.

#### FURTHER READING

- Michael J. Reiss and Roger Straughan, *Improving Nature? The Science and Ethics of Genetic Engineering*, Cambridge: Cambridge University Press, 1996.
- Alan McHughen, *A Consumer's Guide to GM Food: from Green Genes to Red Herrings*, New York: Oxford University Press, 2000.
- Matt Ridley, *Genome*, London: Fourth Estate, 1999.
- John Harris, *Clones, Genes and Immortality: Ethics and the Genetic Revolution*, Oxford: Oxford University Press, 1998.
- Philip Kitcher, *Lives to Come: the Genetic Revolution and Human Possibilities*, New York: Simon & Schuster, 1996.
- Theresa Marteau and M. P. M. Richards (eds.), *The Troubled Helix - Psychosocial Implications of the New Human Genetics*, Cambridge: Cambridge University Press, 1996.
- Dan W. Brock, Allen Buchanan, Norman Daniels and Daniel Wikler, *From Chance to Choice: Genethics and Justice*, Cambridge: Cambridge University Press, 2000.
- Julian Morris (ed.), *Rethinking Risk and the Precautionary Principle*, Oxford: Butterworth Heinemann, 2000.
- Onora O'Neill, *Autonomy and Trust in Bioethics*, Cambridge: Cambridge University Press, 2002.
- Graeme Laurie, *Genetic Privacy: a Challenge to Medico-Legal Norms*, Cambridge: Cambridge University Press, 2002.
- David B. Resnik, *The Ethics of Science: an Introduction*, London: Routledge, 1998.