DNA, Data and Ethics

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In discussions about genetics and ethics, a nexus of material is encountered which refers to a central component, the genetic material, DNA. Some discussions touch on DNA only tangentially; for instance, discussions on prenatal diagnosis of disease and its consequences are often more about reproductive medicine than genetics or DNA. But there are three quite distinct and recent developments which concern DNA itself. They are the development of DNA fingerprinting, the development of medical and DNA information banks such as the DeCode project in Iceland, and DNA sequencing initiatives such as the Human Genome Project. I am grateful to Catherine Cowley for raising some issues in relation to these developments,[1] which I will try to address in this paper.

One really significant problem, often overlooked by commentators, is that these developments involve using different physical techniques for treating DNA. This results in qualitatively different kinds of information and provokes different ethical questions as a consequence. These differences in laboratory techniques, and the information on DNA that they give, do not seem to have been taken into account in recent discussion on the ethical problems raised by DNA technology. In order to enter into an informed evaluation of some of the ethical debate in this area, it is necessary to consider the technical issues in more detail.

1. Three main approaches to analysing DNA ; fingerprints, single gene hybridisation and full sequencing.

Until about 20 years ago, DNA could only be extracted from relatively large amounts of fresh tissue, and then only with some difficulty. Recent developments in technology, particularly PCR, the polymerase chain reaction, have allowed the successful extraction of DNA from tiny samples, such as a single hair, a smear of blood, or a trace of saliva. (There must be some intact cells in the sample, so DNA cannot normally be extracted from urine or nail).

Once the DNA is extracted, it can be examined in a number of ways, each yielding a different kind of information. DNA is an enormously long chain molecule, with a small number of subunits repeated in complex patterns, often called sequences. Some of these specify the structure, or code, for proteins and some do not. All cell activity in all living organisms is controlled by proteins specified by DNA; hence it is often described in terms such as the 'blueprint of life'. Human DNA consists of a large amount of non coding DNA, that is, chemical sequences which do not code for proteins or any cellular component, and whose function is thought to be structural. A much smaller proportion (less than 5%) of the DNA codes for the proteins and other constituents of the body. These coding sequences correspond to what we think of as genes (-and it is therefore true that most of our DNA is not actually our genes).

There are three main approaches to analysing DNA, described as follows. In the first approach, the DNA can be simply cut up into fragments of different sizes,

[1] C. Cowley, *Biobanks, Rapid Response 3/01/06*.www.heythrop.ac.uk/HIREPL, accessed 24/06/06.

and techniques applied to visualise the resulting pattern.[2] This pattern of DNA fragments of different sizes observed is, to all intents and purposes, unique for each individual, and can therefore be used to identify the presence of an individual. This procedure results in the so-called "DNA fingerprint". Further, paternal and maternal elements can be identified and it is therefore possible to decide if two individuals are related by comparing their DNA fingerprints. (It is also theoretically possible to use statistical techniques to try to estimate the probability of an individual belonging to a particular group or carrying a certain gene sequence, but these techniques cannot be very precise, and never definitive).

Overall, the DNA fingerprint does not give any direct information as to the nature of the genes coded for by the DNA, and it gives no information about the chemical sequence of the DNA. It does, however, give direct information about the identity of individuals, including their relatedness. It is widely used by the police in forensic investigations, where the question of identity alone is at issue.[3] This kind of information relates to what might be called 'forensic identity', answering the question 'who has been present' ?

A second approach is widely used to determine the presence or absence of a gene sequence associated with disease. The DNA must be treated differently and must be probed with a DNA fragment of the gene or specific coding sequence in question, or one known to be closely associated with it. This is the procedure offered for tests in hospital for a small range of specific inherited conditions, and in larger research projects. A separate probe must be used for each gene sequence sought. This kind of individual gene hybridisation shows the presence or absence of a specific gene, and can also give information as to individuals' relatedness, as well as to relatives' possible risk of disease. The DeCode project in Iceland is an attempt to record all such tests in one country, together with complete medical records and DNA samples from the whole population, so that continued research can be pursued.[4]

The third approach allows the complete chemical sequence of all the DNA of a particular individual to be obtained. This is a lengthy and expensive process, and has so far only been done in research – eg, the Human Genome Project. However, even this is more problematic than it might appear. The coding sequences of DNA which we call genes are recognisably different from each other. For many of these coding sequences, there is one commonly found sequence and several minor variants which nevertheless lead to normal function of the individuals possessing them. About a third of all genes show such variation. And therefore, if the DNA from two different humans is examined, the coding sequences will diverge where one or other person has one of these minor variants. About ten percent of the total coding sequence will be

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[2] This is done by "probing" or hybridising the DNA under test with DNA of a specified type. Under appropriate conditions, this probe DNA will bind to any part of the test DNA with the same sequence. The use of radioisotope labelled probes, or probes tagged with visual markers, allows the pattern of binding to be visualised. In the case of DNA fingerprints, the probe DNA consists of the some of the common sequences of non coding 'satellite' DNA. These sequences occur in all humans, but with variable numbers of repeats.

[3] A useful account of the history of DNA fingerprinting and its application has been given by its inventor, Alec Jeffreys (2004).

[4] It seems that the UK Biobank, which was promoted initially as a similar DNA based project, has changed direction - Alok Jha, 'Blood, sweat and tears', *Education Guardian*, April 18th 2006, p11.

different in such a comparison. In addition, there are a much smaller number of sequence variants that are actually associated with inherited disease. There is therefore no such thing as the definitive human genome; since all individuals will have a sequence unique to them. The 'Human Genome' actually refers to the range of possible satellite sequences that are variably repeated, and the range of possible coding sequences in healthy individuals, and is dependant on the samples of such individuals that have so far been sequenced completely.

In the case of these latter two kinds of DNA information, the information given is not about forensic identity, but instead, about personal biochemistry and risk of disease, which extends to relatives. This is a kind of 'risk identity', asking the question 'what might happen?' and giving information about the probabilities that an individual has or will develop certain biochemical states and related conditions or illnesses.

All three kinds of DNA analysis give primary results which can appear as photographs of gels or radiographs, which can be stored, or, more recently, as computer images. Computers are essential for any large scale comparison or analysis of results and their interpretations.[5] The extracted DNA can also be stored, and is a fairly stable compound. Blood and tissue samples can be stored, but are less stable than the purified DNA itself.

The current applications of these techniques centre on forensic science, medical research and industrial development. In the forensic field, police forces all over the world have taken up the use of genetic fingerprinting. In the UK the police have the right to collect and use, from anyone suspected of a crime or merely present at a crime scene, body tissue, DNA and information on identity extracted from it. While many DNA samples taken are for the purpose of elimination, nevertheless, whether or not the suspect proves to be implicated in any way, the police may store this information on identity on a database and use it in relation to any other crime. In the area of medical and industrial development, both publicly funded research groups and pharmaceutical companies have established several major databases of partial DNA sequences from large cohorts of related people, in order to advance research into both inherited diseases and normal gene function, and to develop profitable techniques applicable to inherited disease. There are also several databases of complete human DNA sequences.

The consequence of all this is that from one person, traces of bodily material that might formerly have been considered in the category of waste products, can now yield a storable and analysable chemical, which can give a range of information. This can be about forensic identity, or about risk, such as genetic predisposition to disease, or other inherited features such as blood groups, and this information can affect others besides the individual from whom the sample came. The information can be processed by computer, allowing instant retrieval from globally distributed locations. It should perhaps be noted that there are some things the new information does not do; for instance, the knowledge of the complete sequence of the human genome does not allow scientists straightaway to identify every gene, the protein it produces and the

[5]And this itself is controversial; for instance, Marturano and Chadwick (2004) suggest that the use of computers is having a determining effect on public policy making on genetic information issues.

function of that protein. Alas, the project was initially oversold in this respect; the vast majority of sequences are still of unknown function. Similarly, although the cure of disease is one of the ultimate goals of this project, I am not aware of a single cure for disease that has yet been found as a result of the new information. With this caution in mind, we may think of a number of new legal and ethical questions which arise from these new kinds of DNA based information.

Some of these questions focus on the individual. For instance, who, if anyone, owns - the primary body tissue ? -- the DNA extracted from it? -- the information as to identity obtainable from that DNA? -- the information as to potential health obtainable from that DNA? -- any other information obtainable from that DNA? Who can give or withhold consent to DNA, or information, being extracted? Some other questions concern the wider community. Who is entitled to know, or not to know, information about identity or risks to health ? Who is entitled to use, and for what purposes, any or all of the above information? ? And whose interests are concerned in such possible ownership and use? [6] In the ethical literature there seem to be two poles of ethical thinking applicable to these new situations, which I now discuss.

2. Human DNA as private property

One kind of ethical approach to these issues is essentially modern, and originates in Locke's defence of the individual's right to extend themselves by appropriating to themselves the results of their labour. In this case, the concept of ownership is prior to society, which comes into being because of the need to defend property. This kind of argument leads to a stress on defending the integrity and privacy of the individual, and such arguments seem often to be found in discussions of forensic data banks of DNA fingerprints. In a review of ethical issues in genetics, Thomas Shannon suggests that information about an individual's genome is now effectively in the public arena, that this information has wide social and economic implications, and that in the USA at least, this has implications for the traditional concept of privacy.[7] Concern about the use of police DNA fingerprint databases for inappropriate individuals has also been an issue in Europe. A recent example is the case of Benjamin Deceuninck, an environmental campaigner who was arrested in France for disturbing genetically manipulated beetroot plants. He declined to give a DNA sample for the French national DNA fingerprint database, and his refusal being deemed unlawful, he was consequently fined.[8] Freedom to campaign politically might well be compromised if police forces have access to information on the forensic identity of those involved. In a paper typical of the ethics literature on this subject, Judith Wagner DeCew provides a reappropriation of privacy in the context of DNA and information in medical databases and projects. She argues that privacy is necessary for freedom, independence and the "nurturing of creativity" of the human person. She asserts that

[6] The question of interests, looked at from a sociological point of view, would take up a paper on its own. Elsewhere, I have used the theologically grounded analysis of Jacques Ellul to look at the question of genetic engineering in relation to the environment, and I think it would be similarly revealing applied to the DNA based information under consideration here. (Stewart, 2003)

[7] Shannon, TA, 1999: 123

[8] http://publish.indymedia.org/en/2006/09/847499.shtml Accessed 8/10/06

> privacy is a shield protecting us from scrutiny, prejudice, coercion, pressure to conform, and the judgement of others.[9]

She regards genetic information as analogous to medical records, and suggests that the computerised storage of records in databases has led to a major threat to privacy.

> At every stage of the process of collection and storage, dangers can arise, including entry errors, improper access, exploitation, and unauthorised use. Secondary use and aggregation of data are all easier, faster, and less expensive, and thus pose additional threats to an individual's control over the disposition of medical and genetic information.... The rapid and sophisticated ways that data can be updated, changed and configured with few restrictions on dissemination and use, combine with the difficulties of getting rid of data that is obsolete or inaccurate, make privacy concerns for medical information appear virtually intractable.[10]

DeCew cites the example of the Beth Israel Deaconess Medical Center where open access to electronic records is the default, and accountability for this is measured after the fact, with monitoring . There is, of course, no technical reason why a system should not have hierarchical pass words, so that privacy is the default and open access has to be elected. DeCew considers statutory attempts at regulation of such databases, including European legislation upon which the UK data protection act is based. She also considers the process of corporate self-regulation, whereby the proprietors of the databases police themselves. She concludes that in the USA, this has been insufficient to defend the interest of the patient. She recommends a hybrid system in which national legislation requires databases to use procedures which protect the privacy and rights of patients as the norm, but which allows negotiated departures from this with patients' informed consent. She acknowledges that this has both the advantages and disadvantages attendant on the issues surrounding informed consent. Nevertheless, she concludes that this would be the best approach to protect the privacy of medical and genetic information on individuals in the USA and she argues that this approach guards the value of individual autonomy which is fundamental to her ethics, while still allowing new technology to advance.

3. Communal use of DNA information for the 'common good'

The second ethical approach is derived principally from Aquinas' synthesis of Scripture, tradition and classical philosophy. The origins of this kind of argument make it potentially compatible with a theological approach, even when it is presented in a more secular form. On this view, ownership of property is a right to use, not a right of absolute disposal; it is an aid to the right ordering of society, not a constituent of humanity. Communal use has priority in cases of need, and a teleology derived from natural law applies, so that the ultimate goal is always the flourishing of the human community. Arguments with this foundation, about the necessity for the subsidiarity of the individual to the common good, are often found in discussions of risk identity derived from DNA data banks used for research into human disease.

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[9] DeCew, 2004:5
[10] DeCew 2004: 6-7

For example, in one of the 'Ethical Eye' series from the Council of Europe, Bartha Knoppers argues that the human genome is best seen as a common heritage, rather than disputed property.[11] She argues that European legislation has so far not defined genetic material as either part of the person or property, and that irrespective of such classification, legislation does not prevent patenting of certain DNA sequences. She was chair of the Human Genome Organisation (HUGO) Ethics Committee, and cites its statement on benefit sharing, arguing that humans have genomic material in common, that global resources have been viewed as common to all since Grotius devised a law of the sea on these principles, and that where there is an imbalance in power between those providing material for research and those profiting from it, benefit sharing is a functional method of resolving potential injustice. She gives examples of such benefit sharing, for example that the state of Iceland has negotiated free use for the whole population of any pharmaceuticals discovered by using the Icelandic DNA database. She further cites the 1997 UNESCO Universal Declaration On The Human Genome And Human Rights, which considers the human genome to be "in a symbolic sense the heritage of humanity". She regrets that this has not been more strongly translated into law. She concludes that while property law and law relating to the person cannot prevent industrial appropriation of genetic information via patenting, the concepts of benefit sharing and common heritage can be used to counter any injustice arising from such appropriation. She asserts

> The time is ripe to move forward beyond the reification or sanctification of human DNA. We need to examine and harmonise the conditions of consent and control at the level of individuals within countries as well as ensuring international surveillance at the level of the common human genome..... such discussion will probably have greater impact that the current sterile polemic surrounding "ownership".[12]

In a recent paper, Esther Reed pursues similar questions, and in the context of the Human Genome Project, explores the work of Grotius, who established the foundations of the international law of the sea in the early 17th century. She characterises Grotius as

> a Janus figure who looks back to a coherently theological vision of the relation between natural law, the law of reason, and human law, and forward to the unhappy coincidence between subjective rights and property interests in the modern period. [13]

Reed draws a parallel between the status of the sea in the time of Grotius and the status of information on the human genome sequence in the present day. Should it be accessible by all? What 'rights of necessity' apply where gross inequalities between rich and poor appear? What 'use rights' are in the common interest? She argues that the nature of genetic information raises ethical questions that cannot be solved simply in terms of private property, and her critique converges on that of Onora O'Neill, (2004) which I will discuss later on, when she says

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[11] Knoppers, 2004
[12] Knoppers, 2004:115-116
[13] Reed 2006:43

> The interfamilial implications of genetic information and transgenerational consequences of decisions about reproduction raise questions beyond ethical concerns for individual privacy and autonomy. DNA data banking at the level of populations rouses ethical suspicions because of claims that it could become the "pseudo-science" of racism and exacerbate discrimination. [14]

Grotius follows on from Aquinas in assuming a form of natural law, but he regards human survival as requiring a form of self-love, leading to the acquisition of what is necessary for life. The right to property is a permissive right of usage, in keeping with such natural law. Furthermore, divine providence causes human beings to live in community, and appropriate laws are necessary to promote social harmony. So laws recognising common rights and regulating trade are necessary, but Grotius always recognises the pre-eminent claim of the common good in marginal or emergency situations.

Reed approves the parallels with Grotius drawn by Knoppers, and notes that the 2000 HUGO Ethics Committee Statement referred to above uses the concepts of common heritage and benefit sharing, which are more concrete than the earlier statement from UNESCO in 1997 on the same theme, where the human genome is spoken of as a heritage of humanity in a symbolic sense only. She points out that initially access to the human genome sequence was to be public, and that the 1996 Bermuda Statement on this is in harmony with Grotius' principles of contribution to the common good. However, at present no international treaty or agreement actually requires this to be made concrete. President Clinton and Prime Minister Blair stated that sequences resulting from publicly funded research would be deposited in the international GenBank, but they made no legal requirement for any privately funded or industrial project to do the same. There was consequent controversy when some major private companies refused to make their sequences public. Reed suggests that Grotius would have argued for legislation to ensure open access.

She also recognises that the concept of the common good is capable of abuse, particularly where state monopolies exist. But she argues that in contemporary times, the state is necessary to balance the power of market forces, and must educate and regulate in order to protect the citizen.

Reed also looks at the application of principles from Grotius to the question of the patenting of gene sequences, and comes to the conclusion that he would support the contemporary distinction made between a discovery, which describes an existing state in nature, and an invention, which goes beyond nature. The former is not patentable; the latter is. Consequently, she concludes that human gene sequences as such should not be patentable.

4. Problematic aspects of both 'common good' and 'private property' approaches

Neither of these approaches provides a definitive answer to the problems raised by the availability of the new DNA derived information. Onora O'Neill (2004)

[14] Reed 2006:44

points out some of the problems of the private property approach. In terms of forensic identity, is genetic information more sensitive than the information driving licence or in a passport? O'Neill argues that it is not the nature of the information that is important, but the use to which it is put. Further, in terms of risk identity, not all aspects of genetic information are private. We do not normally hide our hair or eye colour, and gender is a social necessity. So some grounds have to be found to make distinctions between genetic information that can be public and that which must be private.[15] Secondly, as I pointed out in the account of kinds of genetic testing, genetic information about one person may also be information about a relative. The relative must also have some interest in the concealment or disclosure of this information, as it may affect their health or welfare. O'Neill argues that the use of individual privacy as a principle in ethical discussion is inappropriate in the case of genetic data. A further problem she raises is that of timing; a great deal of genetic research is retrospective. O'Neill says

> 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. (2004:181).

At the time of collection of DNA samples, it is not possible for researchers to predict the purposes for which data may be used, because of the rapid advance of techniques and possibilities. Consequently, individual consent cannot realistically be given for what cannot be specifically foreseen. This has certainly proved to be the case in the Iceland database project.

On the other hand, proponents of the 'common good' approach do not usually deal with the question of 'Big Brother' , the possibility of state abuse of techniques such as DNA fingerprinting. Esther Reed, in her development of natural law theory, does not ask if the thought of Grotius can be extended to cover the problems raised by the existence of police data banks of DNA fingerprints. In the UK, political demonstrators who are not necessarily breaking the law can nevertheless be detained by police and samples taken for DNA fingerprints, as happened in the French case mentioned earlier. It is perfectly possible for the police to identify the presence of political protestors at different sites or events. Should the state have such information, which could be used to limit civil protest and action? Is it the case that natural law theory is less able to deal with the potential abuse of authority because of the social contexts of those who developed it? For Grotius, the sovereign has a right to demand that citizens contribute to the common good, and the citizens cannot repudiate their sovereign. It is difficult to see how he could be used to argue for civil right limitations to DNA fingerprint data. Other significant questions arise in respect of data banks holding sequence information involving others than the donor. Here some hard questions may have to be asked about where the common good is to be found. Can the state assume responsibility for saying that if I am predisposed to cancer or Huntingdon's disease, my unsuspecting cousin is to be informed? Or is not to be informed? Who is to be told if my legal parent can be seen to be not my biological parent? These are the classic dilemmas of genetic counselling, and fairly rare, but the

[15] There is an interesting discussion of this and related points by Tavani (2004).

use of computerised sequence databanks may make them a much more pressing social problem.

In summary, the view of DNA and the information it holds as private property may protect the individual from state abuse or industrial exploitation, but it does not allow for the use of DNA in legitimate police work, and it excludes the interests of people such as relatives of individuals with genetic disease. On the other hand, the secular forms of arguments that collection of DNA based information is to the common good, do not protect individuals from external abuse or exploitation.

5. Additional insights from Christian ethical tradition

There is a large and helpful theological literature on ethics and genetics in general, although few authors concentrate specifically on the DNA related issues discussed in this paper.[16] A number of positive insights have emerged. For instance, from the perspective of moral theology, it is clear that attempts to improve human physical well being are to be supported. In a useful paper on ethics and genetics, Mahoney makes this point when he argues from first principles that theological axis of Christianity is its claim of salvation for all in Christ. The healing work of Jesus is a significant dimension of his proleptic mission of salvation. Human medical and therapeutic activity is a participation in that, or extension of it, and therefore the positive impulses behind the development of genetic applications to medicine should be recognised.[17] The limitations of databases containing sequence data, and therefore information on possible health issues, are also anticipated theologically. Any collection or usage of such data should not be such as to damage human dignity [18], and this provides a wider and more flexible context for ethical discussion than that given by legal considerations of privacy. Further, concepts of sin include structural sin, and Mahoney evaluates the problems that may arise out of industry's financial gain from genetic and DNA technology [19]. It is likely that more careful regulation of DNA sequence databases will be required, as the open-endedness which O'Neill notes leads to wider ranging consequences for the individuals involved in their creation, and for others coming after.

However, I think that the most important contribution from moral theology to this debate comes from the particular understandings of the common good in Christian thinking. Jack Mahoney points out that one consequence of Christian belief in creation as planned by God is the limiting or contextualising of what is to be considered as the common good.[20] It must always be seen in an eschatological perspective, so that for example, it may not be distorted by short term political expediency. Even more importantly, in theological thinking the common good is not a kind of lowest common denominator or policy of the greatest good for greatest number. It is not *Gemeingut*, an optimal Rawlsian distribution; rather it is nearer *Gemeinwohl*, a space of fulfillment. It is a struggle to implement a state of affairs

[16] Eg T Peters 1997, T Shannon 1999, M Kaveny 1999, JJ Walter 1999, C Deane Drummond 1997 & 2003, J Mahoney 2003, L Sowle Cahill 2005, Gerald Mannion 2006.
[17] Mahoney, 2003: 742
[18] Mahoney 2003:739
[19] Mahoney 2003:740-741
[20] Mahoney 2003 : 747

which allows for the best development and highest good for every individual.[21] Lisa Sowle Cahill describes the general convergence of theological concepts of common good with secular concepts put forward by bioethicists in the context of genetics generally, and stresses the significance of solidarity as a principle in contemporary theological formulations. [22] It is clear that such theological readings of 'common good' require active intervention to improve health and limit criminality, while also precluding both state and commercial abuse.

I conclude that discussion based on concepts of 'individual rights' and 'common good' can be usefully applied to the different sets of ethical problems arising from the application of the new DNA technologies. However, these concepts are not sufficient in themselves to deal with all the questions that arise. I find that further insights from the Christian tradition help clarify and resolve some of these complex issues. Databases of DNA fingerprints, giving information on forensic identity, undoubtedly have potential for a variety of community benefits (and not all relate to crime; for instance, sadly, the identification of the bodies of victims of disasters). The ethical question raised by DNA fingerprinting are largely to do with the possibilities of abuse by the state or its agents. The strong tradition in law of protecting individual rights has been appropriately applied to DNA fingerprinting but moral theology provides necessary modulation of the ethical debate over their use. Medical and commercial databases of DNA sequences, giving information on risk to the individual and their relatives, have obvious common benefit, but the ethical questions about this kind of information are more often about potential failures in the integrity of medical practitioners or exploitation by commercial interests. Again, theological considerations support the necessity of regulation to prevent abuse of the individual by those with vested interests.

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[21] See Gaudium et Spes , 26 & 74. I am grateful to Kevin Kelly for drawing this to my attention.
[22] Sowle Cahill 2005: 117 -136

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See also

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