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ETHICAL ASPECTS OF HUMAN GENETIC DATABASES: DISTINCTIONS ON THE NATURE, PROVISION, AND OWNERSHIP OF GENETIC INFORMATION

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Abstract. This article examines the controversy surrounding the Icelandic *Health Sector Database* in order to provide an overview of the main ethical aspects of this kind of databases. The background for the discussion is the history of genomic research, which is characterized by a tension between private and public research strategies. After some basic distinctions, arguments for different models of appropriation and control of genetic information are examined. Using some criticisms of *genetic exceptionalism*, I argue that if information about the genome is as ethically relevant as other kinds of developmental information, then many ethical aspects of the *new genetics* are quite old. Not only do we need a theory of justice to account for a fair distribution of the benefits of human genetic databases, but we also need an *ethics of virtue* in order to learn how our societies can be modified so as to achieve greater inclusion for those who suffer genetic diseases.

Keywords: genomic research, genetic information, databases, Iceland, deCODE, ownership, benefits, justice, Locke, Rawls

1. Background

This article is primarily focused on the Icelandic *Health Sector Database* (HSD), an issue that has become a sort of paradigm for many discussions about the ethical aspects of human genetic databases in the "first" world. Its aim is to outline two ways of distributing entitlements to genetic information, to apply both models to the proposed HSD, and to extract some critical comments about the way events may develop. It will only provide an introductory overview of the ethical aspects involved, not a fully normative proposal.

The HSD project has been widely discussed in the bioethics literature, and may even provide a useful model for any ensuing discussion about the confidentiality of genetic information (Moreno 2002), but there are not many comprehensive ethical theories able to tackle this kind of issues. Perhaps the most important is the

one published in *From Chance to Choice: Genetics and Justice* by Buchanan, Brock, Daniels & Wikler (2000). These authors provide a coherent argument to support two claims. First, that we should use genomic science to cure disabilities in respect to some basic human functions, but not necessarily to improve human abilities beyond that threshold. Second, that society should increase its respect to those with a disability, but that this should not prevent us from treating serious genetic disorders. This is what many people believe as a matter of course, but the contribution of Buchanan *et al.* is important because they systematically explore those two themes within a liberal theory of justice; that is why the book is specially valuable for any discussion of genetics and justice in liberal societies (such as Iceland is in many respects), even if it is more focused on genetic intervention or engineering than on genetic research using databases and other bio informatics tools. Buchanan *et al.* also claim to have something to say about attitudes toward genetically based disabilities that members of a society must exhibit if our new tools are to be used justly (2000:15), but they do not provide a full account of those virtues necessary to prevent the exclusion of people with disabilities. I would like to emphasise the need of such a supplementary approach, centred on the virtues most appropriate for those responsible and participating in genomic research. But first a few basic distinctions are necessary.

1.1. The question

The management of genetic data, the distribution of knowledge and the flow of information are all issues "important" to *deCODE genetics*, the company licensed to operate the Icelandic HSD. According to one of its press releases, deCODE defines itself a company using population genomics to "create a new paradigm for healthcare [...] turning research on the genetic causes of common diseases into a growing range of products and services" (2002). However, the company believes that, in order to achieve its mission, "this often requires that an intellectual property be secured, which may delay publication of a discovery." For Kári Stefansson, CEO of deCODE, the choice between early publication and the development of a commercial product for the benefit of patients is "an easy one" (Gulcher and Stefansson 2000). However, the question is not that easy. How can "intellectual property be secured" in human population-based databases containing medical and genetic information?

1.2. Some definitions

Although the HSD has not been fully implemented in Iceland yet, as a scientific and commercial project it already exists both in legal texts and in social perceptions. Turning to the former, the Council of Europe defines *genetic data* as "all data, of whatever type, concerning the hereditary characteristics of an individual or concerning the pattern of inheritance of such characteristics within a

related group of individuals." This definition, which is roughly the same as the one in Icelandic law, includes genetic information obtained both from analysis of the individuals DNA and in other ways (Hartlev 2000:76).

According to the "Bill on a HSD" (IMH 1998: art. 3), the database run by deCODE is defined as a "collection of data containing information on health and other related information, recorded in a standardised systematic fashion on a single centralised database, intended for processing and as a source of information." In this definition the word "information" is used both to designate (1) a raw material and (2) a desirable product. So to avoid confusion, here I shall restrict my use of "genetic information" to the second meaning as *any valuable, non-obvious, and novel result of medical research concerning genetic data*. In other words, here I am not concerned with problems about how genetic data are "harvested", but with other kind of bioethical (and bio political) questions: once those data become a social good, how should this be distributed? After all, genetic information is a social good whose value is expected to be high at least in three main areas: (1) genetic tests, (2) pharmaceutical products relying on genetic technology for production or delivery, and (3) gene therapies. Accordingly, there is considerable interest in securing patents or other intellectual property rights over those products (Murphy 1998:202).

2. Two models for the ownership of genetic information

The debate, though, is not about patenting the genome (the human genome is not any more patentable than the human skeleton would be), but particular techniques (including those using databases) that are used to identify its DNA sequences (genes). Of course, the logic of the patent process may ultimately keep genes entirely within the public domain, given that, as genetic research advances, many of its products and processes may be increasingly recognised as obvious (Murphy 1998: 203). Still, some of them may become intellectual property if they satisfy the criteria of novelty, non-obviousness and utility. It is to these processes and products that I shall henceforth refer to as *genetic information*.

2.1. The Lockean model

In *The Second Treatise of Government* (1690: §26) John Locke wrote that man can appropriate property provided he leaves enough and as good for others. This proviso, in **addition** to labour, first occupancy or some other weak claim-generating activity, is offered as a sufficient condition for the original appropriation of something that was not owned before. Its rationale is that if nobody's situation gets worse, then no one can complain about another individual appropriating part of the commons. Applying this Lockean line of argument to "intangible" works or goods, such as genetic information, Adam Moore (2000:100–3) would justify moral and legal rights to control "intangible property" in the following way: When

an individual generates such a good, then her labour or possession creates a prima facie claim to the good; if the proviso is satisfied (that is, if no-one is harmed), the prima facie claim remains undefeated and moral rights are generated; eventually, legal rights should be enforced in order to establish a private domain free from governmental or societal interference. It is to this private domain that the trade of genetic information, both at the individual and corporate level, properly belongs to. This principle might sound simplistic, taking into account the many problems that principle-based approaches to ethics must face (Childress 1998:70). Still, looking at how it is applied to our initial question about securing intellectual property in HSDs, one could say that *this model is widely used as rhetoric*.

As we have just seen, Moore's account of property rights provides a justification for parts of the common stock to be transformed in private property. Similarly, what is at stake in the Icelandic HSD is the appropriation of a part of the common stock (the medical and genealogical information of the Icelandic nation, to start with) in order to produce genetic information that, first, would become deCODE's property so that, at a later time, it can be sold to and used by other companies and, meanwhile, return some benefits to Iceland. That is roughly the deal, and as such it has been approved by the established political procedure. Now, can it be morally justified?

2.2. Problems with the argument for private ownership

The rationale behind deCODE's deal was summarised by Iceland's Medical Director of Health in the following terms: the database "must be implemented without hurting people", and without forgetting "that medical research ultimately and primarily benefits one group of individuals, namely the patients." Of course, he added, "the benefit of a research tool of this kind is general, namely the benefit derived from potential new knowledge." However, there are no benefits or harms for individuals, given that "specific information and test results on a individual may not and cannot be extracted from the database" (Gudmundsson 2000:73, 66).

Some defenders of the database claim that the deal is justified following the Lockean model used by Moore: in the short term, the deal benefits the company and hurts no individual; in the long term, it benefits the patients and the Icelandic nation in general without causing any predictable harm. Not only will it lead to a reverse brain drain as well as to a better management of Icelandic public health system; the whole international scientific community will also benefit by deCODE's pioneer testing of the extent to which the so-called "new genetics" will affect the delivery of health care.

Opponents, on the other hand, claim that putting genetic information in the hands of a private company – one that is not exclusively committed to serve the public interest – is highly dangerous. They add that benefits from the HSD will accrue to only a few Icelanders, and that it will only take the form of a few highly paid jobs. The government's annual licence fee will not prove to be a net benefit to the country as a whole. And, in the future, if advancing technology makes the

database incredibly lucrative, Iceland will receive only a minimal benefit from these developments (for a more comprehensive account of the opponents' position, see Zoëga and Andersen 2000).

It seems clear enough that, as Ruth Chadwick once concluded, the case for the database ultimately depends upon "an articulation of benefit, or of what 'benefit' might mean" (1999:444). However, benefits need their time to arrive – we have to "wait and see" – and yet Moore says that the taking is permitted only if the acquisition of genetic information makes no one else worse off in terms of her wellbeing compared to how she was *immediately* before the acquisition. All this "waiting and seeing" that Locke enthusiasts must do when applying their principle is a real problem, and it casts many doubts about the adequacy of this model.

In the deCODE deal, it might be the case that no individual is harmed *immediately* after the acquisition of genetic information; however, this does not mean that harmful consequences cannot occur in time. First we build the database; then we "wait and see": as the Director of Health wrote, "before judging the process one needs to examine the implementation of the database" (Gudmundsson 2000:73). But once the acquisition has been legitimised and legalised, and the database is built and running, then the Lockean model cannot be used to restore things back to the initial situation, for that would bring harmful consequences to those who were initially benefited by the deal. According to Moore, there had to be at least one individual benefiting by the acquisition of genetic information; to send the information back to where it belonged before the acquisition would harm at least this individual, and probably other people as well (e.g. deCODE's employees).

Because bioethical issues concerning genetic information are characterised by its novelty and uncertainty, responsible scientists should use their imagination to envision future developments and consequences, and to determine which are ethically relevant. To do that they need to empathise with those affected by research and its application, and this requires a moral sensitivity. In this sense, *knowledge is not enough*. As Bertrand Russell put it, "It is impossible in the modern world for a man of science to say with any honesty, 'my business is to provide knowledge, and what use is made of the knowledge is not my responsibility'" (Nordgren 20001: vi, 85).

2.3. The Rawlsian model

Responsible geneticists must provide their fellow citizens not only with knowledge, but also with fair terms of co-operation. Seeking to provide a blueprint for those, Colin Farrelly attempts to incorporate the new issues raised by advances in genetic research into John Rawls's general conception of justice, which claims that all social goods are to be distributed equally unless an unequal distribution is to everyone's advantage (Rawls 1971:62). Those social goods include rights and liberties, powers and opportunities, income and wealth, and the basis of self-respect. Natural goods such as health or intelligence are excluded of the distribu-

tion, because they are not directly under control of the basic structure of society. Seeking to mitigate the influence of *natural lottery*, Farrelly believes that advances in genetic research will make it possible now to expand the set of social goods so as to cover natural endowments (2002:78).

In order to manage those goods, traditional property and privacy rights (including intellectual property) are not sufficient. Because of the obvious importance of one's own natural endowments, Farrelly requires inequalities in the distribution of genetic information to be arranged so that they are to the greatest benefit of the least advantaged. He asks policy makers to consider the consequences private and common ownership of genetic information will have on those most in need of genetic tests, genetic-based medicine and therapy. "If private ownership will benefit these people more than common ownership will, then such a policy would be just. But unlike Moore's position, this argument does not begin from a commitment to property rights." (Farrelly 2002:81)

As a matter of fact, Farrelly writes of "the distribution of genes" (2002:80), even if genes cannot really be redistributed in the way wealth is. However, although genes cannot be redistributed, genetic information can, and much of his article makes better sense thus understood. In addition, it is of course very unclear how we are to define who "the least advantaged" are, or to decide the priority between social and natural goods, but those are traditional problems in political theory. And those difficulties do not prevent him from suggesting that "requiring individuals make public their genetic profiles" is more just than "to allow future generations to be born with ailments that could have been avoided by genetic enhancement techniques if such information was available". In any case, "to begin from a position entrenched in rights to property and privacy is to ignore important issues of social justice" (Farrelly 2002:82).

3. Assessing the models

One need not be a Lockean or a Rawlsian to realise the importance of this case. As Farrelly writes, "how these technologies are to be regulated is perhaps one of the most important questions of our era" (2002:82–3). Both him and Moore agree that justice has priority over efficiency in the quest for an answer. Both would endorse Rawls's requirement that the rights secured by justice should not be subjected to political bargaining or to the calculus of social interests (1971:28).

Moore thinks that the threshold for overriding individual rights to genetic information is higher than commonly suggested. But the problem with his model is that it provides a reason *both* to ordinary citizens to withhold their genetic data *and* to deCODE to secure an intellectual property over it, which may in turn delay publication of discoveries. And then we have also the problem of uncertainty, which in time may worsen the situation of the people who traded the information.

On the other hand, Farrelly suggests that genetic information should become a publicly managed social good, so that it can be used to benefit the least advantaged. This does not rule out the privatisation of common property, but

makes it dependent upon the actual benefit of the worst-off. It is not only a matter of having benefits; *whose benefits* are those is a relevant issue for him. This makes a much more stringent requirement than Moore's Lockean model, in which "companies burn the midnight oil and create or discover new and revolutionary medical procedures in order to make profit" (Moore 2000:117).

Will public healthcare suffer the same fate as the midnight oil? Events in Iceland suggest that it is Moore's model that deCODE would like to see in place, and to a certain extent that is the only "new paradigm for healthcare" that they have succeeded in creating: the commodification of genetic information as a profit-driven reality. In an oft-quoted *New Yorker* article (Specter 1999: §11), Kári Stefansson argued that the HSD is his "intellectual property" and therefore he has a right to claim profits from it. So far many Icelanders have trusted him; most are still waiting and seeing, but surely this cannot go on forever.

Still, how to share benefits seems to be the main unanswered question in the current debate on the ethics of research involving genetic (or medical) databases. Even in a contribution which is quite sympathetic to commercial genomics (Cook-Deegan 1997:180), its author concludes that "the problem is [the] distribution of benefits so that inventors and private firms that sell products share the benefits" of a research based on the exploitation of a common resource.

In the Lockean model, private appropriation of genetic information would actually benefit the situation of some people, namely those who appropriate, sell, and buy it. These people are not the least advantaged; Moore is fully aware that "almost every medical advancement at its beginning was available only to the rich" (2000:117). He hastens to add that eventually prices will drop so that those procedures become available to everyone. But even if this hope was realistic, the reason for the prices to drop would still be higher profits.

On the other hand, the Rawlsian model has many problems to solve, but still makes it clear that need, and not profit, should be the engine behind any attempt to justify ownership of genetic information. If private ownership serves the needs of the population best, then let it be. But no matter how lucrative, if those needs are better satisfied by public ownership, then intellectual property and other considerations must give way.

How then can intellectual property be secured in HSDs? One might argue that since the data in the records have been paid for out of public funds, they should not be owned by private individuals or companies; rather, they should be part of the public domain and with no intellectual property involved whatsoever. If this is the case, would it be true then that even opting out should not be offered?

Concerning this kind of questions, and because of an ever-increasing private investment, in 2000 the HUGO Ethics Committee subscribed to the following four principles presented in its Statement on the Principled Conduct of Genetic Research (1995):

1. Recognition that the human genome is part of the common heritage of humanity;

2. Adherence to international norms of human rights;

3. Respect for the values, traditions, culture, and integrity of participants;
4. Acceptance and upholding of human dignity and freedom.

It also recommended "that all humanity share in, and have access to, the benefits of genetic research" and that even in the absence of profits, immediate health benefits as determined by the needs of the participating community could be provided (HUGO 2000). However, if the human genome is "part of the common heritage of humanity", one could deny that it ought to be owned by individuals, communities or companies; rather, it should be part of the public domain. But then, in cases such as the Icelandic where genetic databases are created, why should privacy rights protect the information? After all, is not the HSD a collection of information similar to a nationwide census, where opting out is not offered? (cf. Chadwick 1999:444) To this it can be replied that genetic information is somewhat special, even exceptional, and that this exceptionality justifies specific forms of provision and ownership.

4. How exceptional is genetic information?

Despite its attraction, scientists and ethicists alike have rejected the thesis of genetic exceptionalism. In 1993, a Task Force created by the USA government concluded that "genetic information did not differ substantially from other kinds of health-related information" (Murray 1997: 61). They found no good moral justification for treating genetic information, genetic diseases, or genetic risk factors in a different way. What they found is that the more we repeat that genetic information is fundamentally unlike other kinds of medical information, the more support we implicitly provide for *genetic determinism*, for the notion that genetics exerts a decisive power over our lives (Murray 1997:69, 71).

This reason has more to do with sociology than with biological science, but biologists have also criticised some unqualified versions of genetic exceptionalism. Because genes and environments are no different in terms of their effects on development, Tim Lewens concludes that the new genetics presents no new ethical problems that have not been encountered before, through our long-standing practices of modifying the developmental environment. This is not without consequences, for then many arguments in favour of the redistribution of educational or nutritional resources become arguments in favour of the redistribution of genetic developmental resources through genetic intervention (Lewens 2002:206).

There are other reasons to be especially cautious of genetic information, though. Lewens defends a qualified version of exceptionalism because genetic information is easy to capture from a cell, and because cells are easy to capture. (Also because one's environment cannot be sequenced in the same way as one's genome). But, after reviewing better and worse reasons to qualify the argument for intervention, he concludes that the argument holds even if genetic engineering is the blunt tool that we have today, for it can be improved. It also holds even if the redistribution of genetic resources is eventually impossible, for information about

the genome should then be used to better redistribute developmental resources. Of course, we might discover that the genome is a poor place to intervene; or that intervention may be used in a biased or distorted way. And we should never forget, he claims, that to always look to genetic intervention to equalise opportunity, or resources, or welfare, is to ignore social deficiencies that sometimes stand in need of remedy (Lewens 2002:213–4).

5. The provision of genetic information: tensions in genomic research

For Lewens, then, genes should fall into the calculus of distributive justice; as we have just seen, this is a task some philosophers have already attempted to do. But in order to be distributed, social goods must be created first. Because genetic information is today being provided and accessed, while genetic engineering is still being more discussed than realised, a focus on research seems to be more relevant than a focus on intervention. Turning to research, its main feature is an obvious tension between private and public strategies. For instance, it is expected that as commercial interests play a larger role in genetics, access to genetic information will become more and more restricted for profit reasons, at least in the USA. Some argue that this will prevent scientific progress, while others argue that the privatisation of genetic information is needed to generate the necessary funding to bring products to the market (Marks and Steinberg 2002).

A brief sketch of the reasons for and against the privatisation of research would include the wish to obtain patent rights, to retain exclusive access for customers, and to avoid disclosure to rivals. On the other hand, the scientists' desire of recognition and credibility for their discoveries is a reason for converting the results of genomic research into a public good. Others might choose to disclose genetic information in public databases in order to promote widespread dissemination and use. Finally, publicly funded investigators are normally required to deposit all their findings in the public domain.

Another important factor contributing to this private versus public tension is to be found in the policy of the USA government, beginning with the passage of the Bayh-Dole Act of 1980, which promoted the patenting of government-sponsored research results. The legal situation in Europe is more ambiguous and depends upon national laws in response to a 1998 directive of the European Parliament on the legal protection of biotechnological inventions (Eisenberg 2000).

So far we have examined the nature, ownership and provision of genetic information. Let us now recapitulate some ethical aspects of our discussion.

6. Conclusion

The criticism of the notion of genetic exceptionalism suggests that information about the genome is as ethically relevant as other developmental information such as educative resources, population census or income data. If those criticisms are

correct, genetic information will be only valuable in the form of knowledge about the interactions of specific genes with specific environments. This is what according to Buchanan *et al.* (2000:298ff.) the new genetics will teach us: that individuals with particular genotypes require particular environments, both physical and social, if they are to flourish. Because in some cases the needed environment will not be the one that exists now, questions of distributive justice emerge.

Genomics is a battlefield for complex research strategies and conflicts of interest. Public provision of and access to genetic information advances some interests while harming others, with no simple distinction between the interests of public and private institutions, between public and private goods. There are reasons to keep genomic research public and reasons to keep it private, suggesting that both private funding and public availability to results are important. Some kind of compromise seems to be necessary, as is increased dialogue between private and public interests in order to ensure the continuity of research in medicine and life sciences.

The applied Rawlsian model proposed by Farrelly has many problems to solve, but still makes it clear that the duty not to harm (*primum non nocere*, one of the most basic principles of medical deontology), and not commercial profit, should be the primary engine behind any attempt to justify ownership of genetic information. If private ownership serves the needs of the population best, then let it be. But, no matter how lucrative it might be, if those needs are better satisfied by public ownership, then intellectual property and other considerations must give way.

However, and because of the problems that principle-based approaches to ethics must face, it is very hard indeed to settle specific problems of ownership using general principles such as the Lockean or the Rawlsian ones (Bergström 2000: 107ff). And the *third approach* (between the public health model and the private personal service one) offered in *From Chance to Choice* is focused in institutional principles for genetic interventions, not in genomic research using databases.

Research using human genetic databases raises questions of justice not only about the genome, but also (and primarily) about the environment. No matter what theory of distributive justice is to be applied, Buchanan *et al.* (2000:260, 298ff.) argue that genomic research may help to better understand some old debates; instead of asking bad questions, such as "Which is more important (for this problem, this characteristic), genes or environment?", the question should be "Which combinations of genes and environments will produce the desired outcome?" Their hope is that proper genomic science, the study of how human genes and environments interact, will enable us to identify and create the most beneficial environments for achieving desired results, specially that of having more individuals as effective participants in society. This final *morality of inclusion*, they think, is a topic neglected by contemporary ethical theory.

However, since classical philosophy the acknowledgement of disability has played an important role in ethics. For Aristotle, the ethical domain is the domain of deliberation and choice in search of the good life; in this search, "we deliberate about things that are in our power and can be done" (*Nic.Eth.* III.3), and even if the new genetics provides us with new things to deliberate upon, this does not

represent new ethical problems. How to achieve greater inclusion, and how to distribute resources, are open questions, but very old ones.

Alasdair MacIntyre (1999) has argued that rational consideration of the pervasiveness of human disability stimulates both personal and social virtue, because disability (and the dependence that it causes) is a common and permanent feature of human existence. In so far as genetic information might show that some people have or have not the potential to share certain disabilities, the new genetics provide new weapons for exclusion, because it breaks with the traditional understanding of disability as a condition we all have the potential to share. Buchanan *et al.* do not deny this, even if they see nothing exclusionary about the improvement of human lives through the application of genetic knowledge. What they see at this point is the necessity of a shift from questions of distributive justice to an ethics of virtue, in order to learn how can our societies – and above all our attitudes toward those who have disabilities – be modified so as to achieve greater inclusion for those who suffer genetic diseases (2000:302).

In sum, how to achieve greater inclusion is not a new question, but it is perhaps the least considered of the ethical aspects of human genetic databases. Thus it remains a key factor in order to achieve a fair distribution of the benefits of genomic research, and to prevent some of the harms that may occur in time.

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