Genetics and insurance: is it "in the public interest" to involve the law?

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Introduction

There is a wide-spread perception that genetic information is unique and therefore different from other forms of personal or medical data. Certainly, a prima facie strong case for this position can be made out in part:

(a) Genetic information relates to families and not just individuals
(b) Genetic information can offer a degree of certainty in determining which of those persons is likely to be affected by genetic disease
(c) Genetic information can provide a measure of predictability in the assessment of likelihood of ill health in particular individuals from an affected group
(d) Genetic information can reveal secrets about future ill health, even in those who are currently well; what Annas has called a 'future diary of ill health'. (1)
(e) Genetic information can help to determine future risks in future persons, i.e. one's progeny.

But, for each of these examples other examples can be given on non-genetic data, or at least data which have not traditionally been considered to be genetic, which also function in one or more of these fashions. (2) This would tend to militate against the argument that genetic data are unique, or in some way special. And, as we all know, as more work is done of the Human Genome Project, the one clear message which emerges is that most diseases have a genetic component, thus potentially relegating most diseases to a sub-category of the ever broadening genus of 'genetic disease'. (3)

Formulating and Implementing Legal Policy

These scientific subtleties and truisms should impact directly on legal policy and the process of law-making. An eminent American colleague of mine who is trained in medicine and ethics, once taught me a very important lesson about my field of research by uttering these simple words about his own: "good ethics begin with good facts". On hearing this, it struck me immediately that the same is true for law. A simple lesson, or so it would seem, but one easily forgotten in the medico-legal realm by law-makers keen to appease a worried public wrestling with complex issues of medicine, science, ethics and law.

Plenty of examples can be found of knee-jerk legislation passed in haste and repented upon at leisure. Two examples from the 1980s include the *Surrogacy Arrangements Act* 1985, passed in the aftermath of the Baby Cotton affair, and the *Human Organ Transplants Act* 1989, which was brought into force very rapidly after the press broke the story of Turkish citizens coming to Britain to sell their kidneys for profit. More recently, the reconstituted Scottish Parliament, which opened its doors on 1 July 1999, will undoubtedly go down in history as the parliament with the Most Rapidly Passed First Piece of Legislation. *The Mental Health (Public Safety and Appeals) (Scotland) Act* 1999 *asp 1* was passed in less than 48 hours, designed to deal with the problem of the non-treatable mentally abnormal offender, ensuring that such persons need not be released even if they are no longer treatable. It is a highly suspect piece of legislation, and its terms have already been the subject of a human rights challenge in the Scottish courts. (4) Nonetheless, its very existence stands as testament to the considerable sway of two factors which can, and often do, influence law makers and legal policy. These factors are public perception and press power. And, in the rush to mollify the public and the press, truth and reason can often be the first casualties of legislation. Moreover, when one is dealing with subjects such as genetics and insurance, which involve considerable intricacies and an interplay of various interests and policies, the room to accommodate subtleties is often lost.

As I have indicated, there is a perception that genetic information is somehow unique and under more threat than other forms of personal or medical information. In particular, two common concerns are those of privacy and discrimination. So, should there be a law on it? As a starting point, it is easy to confirm that there is currently no overarching protection in the UK in the realms of privacy and discrimination that would necessarily extend to genetic information.

Privacy

Two recent legislative initiatives in the UK have brought about a reversal of fortune in the protection of individual rights

and freedoms for British citizens as regards personal privacy.

The *Data Protection Act* 1998 lays down conditions under which all processing of personal data must be carried out, as well as providing for core rights for the subjects of such data and the maintenance of quality data standards. 'Personal data' is defined as 'data which relate to a living individual who can be identified - (a) from those data, or (b) from those data and other information which is in the possession of, or is likely to come into the possession of, the data controller'. (5) A 'data controller' is 'a person who (either alone or jointly or in common with other persons) determines the purposes for which and the manner in which any personal data are, or are to be, processed'. (6) Personal health data, including genetic data, are clearly caught by the provisions of this legislation. Indeed, they qualify as 'sensitive personal data' and as such receive more stringent protection, permitting processing only in limited circumstances, for example, with the explicit consent of the data subject. (7)

But, it is only with the coming into force of the *Human Rights Act* 1998, as of 2 October 2000, that British citizens have direct legal protection of their private lives for the first time ever. How far that protection will extend remains to be seen, for the 1998 Act merely provides a framework of human rights protection, and it falls to the judiciary to put flesh on the bones of that framework. Accordingly, the extent to which 'private life' will be protected, or indeed any of our human rights, will depend almost exclusively on the activism which our judges choose to exercise. Certainly, while there is much scope for development, (8) our courts will find no assistance from the jurisprudence of the European Court of Human Rights (ECHR) in the realm of genetics and the law, for the ECHR has never been called upon to assess the scope of the protection afforded to private life in a sphere such as this. Moreover, and most importantly, our human rights are protected only as against public authorities, not as against private individuals or private entities such as insurance companies, and therefore it might be argued that any protection which is forthcoming is inadequate in the context of genetics and insurance.

Discrimination

Anti-discrimination law in the United Kingdom is governed by three pieces of legislation: the *Sex Discrimination Act* 1975, the *Race Relations Act* 1976, and the *Disability Discrimination Act* 1995. The protection afforded against discrimination by the 1975 and 1976 Acts is restricted to their precise remits - that is, sexual or racial discrimination. Since many genetic conditions are sex-linked or affect particular ethnic or racial groups, differential treatment of afflicted individuals could amount to discrimination within the terms of these Acts, probably as examples of indirect discrimination. It is not clear, however, how successful such arguments would be, there being no cases on point. More opportunities for redress lie with the *Disability Discrimination Act* 1995 which is the first piece of UK legislation to deal directly with discrimination against disabled people. The Act outlaws discrimination in a wide range of fields such as employment, the provision of goods, facilities and services, the sale and let of property, education, and public transport. However, the question arises of whether the provisions of the Act extend to persons whose genome contains defective genes which do, or can have, a bearing on their future health. Persons who are already affected by a genetic condition clearly come within the definition of "disabled person", but what of a person who merely has a predisposition to ill health? The Act would seem to exclude such a person for it speaks of one who '*has* a physical or mental impairment which *has* a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities'. This means, by inference, that discrimination against persons who are currently asymptomatic but who have a predisposition to future ill-health is not unlawful under the Act. This disparity and the question of genetic testing were raised in the parliamentary debates, but the Minster in charge stated:

...except in a few well-publicised cases, genetic tests are not as yet a useful indicator of future actual disability. Their inclusion would open up the [Act] to large numbers of people who are clearly not, and may never become disabled...we cannot wander into a situation whereby, for some reason or another, potentially the entire population could claim protection under the [Act]. (9)

It is certainly true that genetic tests are by no means accurate at present, but that does not mean that such tests cannot be misused by employers and insurers, nor that they will not be used to exclude people from jobs and other services for irrelevant and irrational reasons. Legislation designed to outlaw discrimination on the grounds of disability should cover all forms of discrimination, whether the disability is actual or perceived, current or future. It is arguable that the provisions of the Act as they currently stand are inadequate and are potentially prejudicial to persons likely to develop genetic conditions later in life. The anomolies of the current provisions were summed up by Baroness Jay in the House of Lords,

The paradox which is possible in the present situation is that where genetic counselling, genetic testing and identifying genetic markers is potentially one of the most exciting and liberating developments in medical science at the end of the 20th century, if it becomes the case that people feel that identifying those markers in their own personal situation will lead to discrimination, they will be less likely to take advantage of those extraordinary scientific advances which may help their own condition and in which medical science may be able to help future generations of children. (10)

Addressing the Problems Using the Mechanism of Law

Thus far we have identified potential loopholes in the law. This we might take as confirmation of the legitimacy of concerns about potential misuses of genetic information. But none of this necessarily leads us to the conclusion that it should be for the law to address those concerns by focussing its attentions specifically on genetic information. There are a number of reasons why this is so.

Genetic Exceptionalism: What is 'genetic information'?

It is far from clear that the case for genetic exceptionalism has been satisfactorily made out. While, as I have suggested, some have argued that our DNA acts as a 'future diary' revealing our genetic secrets in times to come, others have pointed to the difficulties of defining 'genetic information' in law, and in separating out what is genetic, and so deserving of special protection, from that which is not. (11) For example, Dutch insurers were recently accused of flouting a law prohibiting discrimination on the basis of genetic information. A study had showed that families in which hypercholoestrolaemia was prevalent had had difficulties in obtaining life insurance, despite the existence of legislation which prohibited direct questions about genetic information. The retort of the insurers was that no questions had been asked about hereditary conditions. They had simply asked if candidates had high cholesterol levels, classically a non-genetic question. (12)

The difficulty of drawing a clear distinction between different kinds of information seriously undermines the feasibility of law designed solely to protect genetic information. All personal data are worthy of respect and protection by virtue simply of the fact that they relate to an inherently private sphere of our lives. In the same way that each of us deserves respect as human beings possessed of human dignity, so too must that respect extend to intimate adjuncts of our personalities, such as personal information, whether it be genetic or not.

If, in the realm of privacy and insurance, the concern of the public relates to the security of information held by insurance companies, it is important to take cognisance of the fact that the Data Protection Act 1998 protects the general class of 'personal data'. Its terms are such that the protection afforded to information which could be used to identify blood relatives from genetic testing would also be extended to those relatives in respect of that information. (13) This would alleviate one potential concern that current laws do not adequately respond to the 'unique' circumstances of genetic information. This having been said, if these data do indeed relate to relatives within the terms of the Act, it should be noted that specific consent of those persons is required to hold the data, because health data are 'sensitive personal data' under the Act, requiring special security provisions. This could be problematic, in that the persons in question might not be easily identifiable or might withhold consent, thereby impacting on the interests of the proband. All will depends on how the terms of the Act are interpreted. For example, what does it mean when 'personal data' is defined as 'data which relate to a living individual who can be identified - (a) from those data, or (b) from those data and other information which is in the possession of, or is likely to come into the possession of, the data controller')?

While this piece of legislation does not exhaust the limits of privacy as a means to protect individual interests relating to one's genetic constitution (as I shall discuss presently), it does go a long way to guarding against abuses of personal data, in ways which do not require to rely on the dubious foundations of genetic exceptionalism. Such a broad, potentially overly inclusive protection for the class of personal data, is arguably preferable to a narrowly defined class of genetic information which would not only be difficult to delimit, but would also run the risk of excluding many forms of information that would deservedly require protection. We must be as wary of a surfeit of legislation, as we should of any instance of bad legislation.

The Realities of Risk

How great is the need for laws to protect against misuses of genetic information? There are a number of ways that we can address this question. Indeed, two have already been mentioned: the public perception of abuse, and the role of the press. Certainly, a number of bodies have noted a concern among the public about the potential uses which the insurance industry, among others, might make of genetic data. For example, while the Human Genetics Advisory Commission went out of its way in its 1997 report on genetics and insurance to praise the ABI for introducing The Genetic Testing Code of Practice, (14) the Commission also noted a strong sense of unease among the public about the potential uses to which the industry might put genetic information. Similarly, the Human Genetics Commission has been asked by the Government to examine the position in respect of genetics and insurance, without any clear steer on its own policy in this area, largely because of the apparent air of concern among the public. Interestingly, however, a number of surveys, both at home and abroad, have found very little evidence of discriminatory practices in insurance . (15) The question then becomes this: if good law should flow from good facts, what should we take from the fact that there is precious little evidence of discrimination in the context of genetics and insurance? Of course, such a lack of evidence does not obviate the risk of abuse in the future, but it should lead us to question whether there is a role for the law in attempting to pre-empt potential abuses. A member of the Australian judiciary once famously said that the law was destined to remain behind medicine, bringing up the rear and limping a little. This was stated in a spirit of disappointment, as if the law was

failing to respond adequately to advances. But I would suggest that oftentimes a position at the rear can be advantageous, especially if, as in this case, common sense has prevailed, as would seem to be the case with the ABI's response to the advent of genetic testing. Taking a back seat, surveying the lie of the land, and reflecting on the range of issues at stake will ultimately make for much better legislation, if this is thought to be desirable at all. Legislation designed to pacify misplaced or unfounded concerns is a sham, and can only serve to fuel the fires of discontent.

A Balance of Interests: What is Discrimination Anyway?

Discrimination refers to differential treatment between groups of people or individuals for irrelevant or irrational reasons. Mere differential treatment between groups or individuals in se is not discrimination. Moreover, the ethical principle of justice which dictates that we should all be treated equally, does not require that we should all be treated the same. While that might appear like legalistic sophistry, the point is that it is *not* discrimination to differentiate between groups or individuals for valid or appropriate reasons.

The focus of this paper is the public interest. My over-arching question is whether it is in the public interest for the law to intervene in the context of insurance and genetics. In order to know what is in the public interest, we must know which interests are at stake. These are relatively straight forward in the present context. For the prospective insured, personal interests of privacy, respect and non-maleficence are in the balance. Taken individually, these interests are private to each of us, but collectively there is a strong public interest that prospective insured persons are generally treated fairly and with respect. From the insurer's perspective, it is primarily financial interests which are in issue, and in a business which is driven by the assessment and minimisation of risk, it is not to the financial advantage of the insurer to undertake unduly bad risks. But, here too public interests are also at stake, in that a high instance of adverse selection among insured persons will only serve to push up the premiums for the general body of insured. Crucial, then, to the assessment of risk for insurers is information. By the same token, the protection of information is vital to the security of individual interests. Issues of legitimacy of access and control therefore arise.

This tussle of public interests is best resolved in the pursuit of balance: public interest v. public interest. In seeking that balance the legitimacy of each set of interests should always be open to question. But, once a prima facie case has been made, the aim should be to strike the best balance possible between the range of interests involved. Thus, for example, following on from what has already been said about the weakness of the case for genetic exceptionalism, a strong case can be made that genetic data which already exist can legitimately be seen as relevant to the assessment of insurance risk. In the same way that other medical tests can produce statistically significant data about future risk, so this might be true of genetic tests. I have, therefore, little problem with the approval by the Genetics and Insurance Committee on 13 October 2000 of the use of test results for Huntington Disease in the assessment of life insurance. (16) Such a cautious and casuistic approach is based on good facts and goes a long way to addressing concerns against abuse. Moreover, this approach operates without the intervention of law, and for that it should be lauded.

The main counter-argument to this approach is that people will be deterred from seeking those tests which might ultimately be used for insurance purposes. But this argument can equally be applied to tests for heart disease, high blood pressure and a plethora of other conditions which are not normally seen as being genetic in nature. Apart from the obvious difficulty of trying to determine who has *not* acted in any given set of circumstances, I am unaware of any serious evidence which would suggest that the public has been unduly deterred from seeking information about its health in these non-genetic circumstances for fear of the impact which this knowledge might have on later insurance assessment. And, even if there is a real risk of people being deterred from taking genetic testing, I am unconvinced that the best way to deal with this problem is to instigate legislation which denies the insurance industry access to that information. In particular I have two concerns with that approach. First, I do not think that individual interests in protecting existing genetic knowledge are sufficiently great to outweigh completely the interests of the insurance industry in gaining access to actuarially significant information. Second, any such law would perpetuate the fallacy about the uses to which genetic knowledge might be put. It would blur the distinction in the minds of the public between legitimate and illegitimate uses of genetic information for insurance purposes, and would affirm a case for genetic exceptionalism which is ill-founded. We should seek to educate, not legislate.

Promoting Privacy: The Limits of Law?

You might imagine that as a lawyer I would be disheartened by the prospect of imposing limits on the reach of law. But as a lawyer trained in the discipline of medical law - a discipline which is informed as much by ethical discourse as it is by legal doctrine - I long ago came to realise that law is not always the answer. Certainly, law is not our only option, and the reality is that a multi-layer approach to most social problems and dilemmas is usually called for. While law can form part of that overall strategy, we should be wary about making it our first port of call, for often solutions are to be found in subtle balances of interests and nuances of approach, and the law's heavy-handed style can make it is too crude a tool with which to crack the particular nut.

But my overall message is not one to exclude law, but rather to explore all of the options before we resort to law. And, as

a final consideration, I would like to examine an area which I think has been under-explored to date, but it is one which has important consequences for how we view the balance of interests which are at stake in the context of genetics and insurance, and indeed, how we might perceive the role of the law in the future.

Up until now I have discussed the legitimacy of permitting the insurance industry to have access to existing genetic information; that is, to genetic test results which already exist. The main thrust of my argument has been that it is difficult to make an argument for treating genetic information as a special case, for in most ways it fits very neatly into the existing paradigm which governs access to personal health information. Thus, for example, the general doctrine of uberrima fides which governs the insurance contract requires that any information which might have a material bearing on the decision to grant insurance should be disclosed. This would apply equally to genetic information, however that might be defined. Moreover, the decision to seek such information through testing is likely to have been one taken by the individual unfettered by other considerations and free from coercive forces. In other words, it will have been a free choice and an exercise of individual autonomy.

But what of a request to seek genetic testing for insurance purposes? How legitimate would this be in the balance of interests? I would like to make a final argument along three lines. First, this would be an illegitimate request, for it would be to tip the balance too much in favour of the insurance industry. Second, it is a position which need not necessarily be restricted to genetic testing. Third, the basis of this argument has not been fully explored in the discourse surrounding the appropriateness of our social and legal responses to advances in genetic science. It is time that we do so.

A Right Not to Know

Why would it be illegitimate to request prospective insured persons to undergo testing? I would submit that such a request interferes too greatly with the core set of interests which individuals have in their selves and the control to which they are entitled over their private lives. Unlike a request to know information which already exists, a request to undergo testing generate new information. (17) Moreover, it does so for reasons which are not necessarily, or even at all, those of the individual concerned. In fact, it is done largely to further the financial interests of the insurance industry. (18) Yet once this information is known, it can never be unknown. It becomes, and remains, a part of the individual's life. And, in many cases, there will be a strong possibility that this new knowledge will reveal information about future ill-health. The impact of this discovery on the psychological integrity of the individual can be very significant. I have argued elsewhere, for example, about the possibility of causing psychological harm by burdening people with information which forces them into a period of self-reflection and self-reassessment which they would not otherwise have experienced. Knowledge of future genetic disease can lead directly to what the Danish Council of Ethics has called *morbidification*: 'the notion of falling victim to some inescapable fate through knowledge about risk of disease'. (19) This can affect the way people feel about themselves, as well as the way they treat their children and the way they view future progeny, all of whom may or may not be afflicted by disease. Indeed, there is some evidence to suggest that there is a tendency for people who are given knowledge of risk of disease to behave as though disease is already present, especially when that knowledge is about a child. Thus, for example, in 1974 the Swedish government abandoned a nationwide screening programme of newborns for alpha1-antitrypsin deficiency because follow-up studies showed that more than half of the families with affected children suffered adverse psychological consequences, some of which continued for 5 to 7 years. (20) Many asymptomatic children were 'victimised', in the sense that they were treated by their parents as though already ill. Consider too, a recent international study which has shown that the suicide rate among persons given a positive genetic test result for Huntington disease was 10 times higher than the US average. (21)

The conclusion to draw is that one should not assume that it is always in a person's best interests to know information about their genetic constitution. In certain circumstances, there may be a stronger interest not to know.

This argument is not restricted simply to genetic information, although in certain cases of highly predictive conditions, the impact might be all the more significant compared with other genetic or medical tests. But, if any special cases is to be made, it should not be for the general class of genetic information, but rather for highly predictive kinds of information, be it genetic or otherwise. (22) Moreover, it may mean that we should revisit the legitimacy of requests by insurers that candidates undergo general medical examinations, for here too information is generated which has potentially devastating implications for individual interests.

I am arguing here for recognition of a right not to know. The existence and nature of such a right has scarcely been explored in the literature relating to genetic information, or indeed, in relation to personal medical information. Yet, it is a right which I believe requires full consideration. To do so will help us better understand the full range of interests at stake when dealing with personal health information, and genetic information more particularly. Moreover, it can help to inform the possible role for the law. I would argue that at present there is no viable means in law to protect this sort of right. It cannot be protected by the right to choose, because the right to choose requires informed choice, and this 'right' is all about not knowing. Likewise, it cannot be protected by the law of confidentiality. Confidentiality is concerned with keeping information about you away from third parties, this 'right' is concerned with keeping information about you away from you yourself. Finally, the Data Protection Act 1998 does not help because it is concerned solely with information which already exists. I have argued elsewhere that, in fact, this right is an aspect of the privacy interests

which each of us has an a human being possessed of rights. (23) To date, however, they have not received full recognition in law. In keeping with the general thrust of my argument, it might be the case that there will be no need to reach that point. The mere introduction of this argument into the discourse might suffice to ensure that the 'right' is duly respected. Indeed, already the insurance industry is at pains to point out that it is primarily concerned with gaining access to existing genetic information, and not that which is yet to be known. However, should we ever find ourselves in the position that access is sought to private information which is in the realms of the unknown, I would offer these arguments as a means of striking the balance that, I believe, represents the best way forward in dealing with the complex issues and interests which surround genetics, ethics and the law.

Conclusion

Like most social constructs, insurance is a cultural phenomenon. The same is true of the law. Thus, our task is to match the most appropriate legal response with the way in which insurance operates within our culture. Our solution, then, will not be universalisable, and indeed, it might not involve the law at all. But, it is the responsibility of all of us to ensure that the solution that we arrive at is the most apposite for the culture in which we live.

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(1) See generally Annas, GJ and Elias, S. 'Gene Mapping: Using Law and Ethics as Guides', OUP, 1992.
[2] For example, as the report 'Genetics and Health' points out: '[h]igh cholesterol levels [are] known predictors of cardiovascular disease, and high blood pressure of cerebrovascular disease risk...without recourse to genetic testing familial aggregation [is] discernible not only in the monogenetic disorders but also in a range of common disorders including heart disease, cancers and diabetes', see The Nuffield Trust, Genetics and Health, May 2000. The report notes that some commentators have suggested that '[I]f special levels of protection were required then it should be in respect of monogenic disorders of high penetrance and not genetic information in general, whether that information came from the results of testing or from other sources'.
[3] As the Chair of the US Task Force on Genetic Information and Insurance has said: 'Genetic information is special because we are inclined to treat it as mysterious, as having exceptional potency or significance [and] not because it is different in some fundamental way from all sorts of information about us.'
[4] Anderson and Others. v. The Scottish Ministers and the Advocate General for Scotland, 16 June 2000.
[5] See, s.1(1) of the Data Protection Act 1998.
[6] ibid.
[7] ibid, s.2.
[8] the European Court of Human Rights and its Commission have interpreted Article 8 very widely to include not merely a right to control personal information (Niemietz v. Germany (1992) Series A vol. 251-B), but also protection of interests relating to physical and moral integrity (X and Y v. The Netherlands (1985) Series A vol.91), the freedom to develop one's personality (Gaskin v. UK (1989) Series A vol. 160), and to establish and maintain personal relationships (Beldjoudi v. France (1992), Series A, vol. 234-A).
[9] Hansard, H.C., Volume 257, col. 887.
[10] Hansard, H.L., Volume 564, col.1713.
[11] Contrast Annas, 'Genetic Privacy: There Ought to Be a Law' (1999) 4 Tex. Rev. L. & Pol. 9 and Rothstein, 'Why Treating Genetic Information Separately is a Bad Idea' (1999) 4 Tex. Rev. L. & Pol. 33.
[12] Sheldon, T.; 'Dutch Insurers Flouting Law on Genetic Disease', (2000) 320 BMJ 826.
[13] If relatives are identifiable from genetic test results of a patient, together with other information held by the data processor, or readily available to her, then the data generated from the test would also, arguably, be personal data of the relatives.
[14] Human Genetics Advisory Commission, The Implications of Genetic Testing for Insurance, (1997).
[15] See, for example, Paul Billings et al., Discrimination as a Consequence of Genetic Testing', 50 Am. J. Hum. Gen 476 (1992); Joseph Alper et al., Genetic Discrimination and Screening for Hemochromatosis, 15 J. Pub. Health Pol. 345 (1994); Lisa Geller et al., Individual, Family and Social Dimensions of Genetic Discrimination: A Case Study Analysis, 2 Sci. Eng. Ethics 71 (1996); Lawrence Low et al., Genetic Discrimination in Life Insurance: Empirical Evidence from a Cross-sectional Survey of Genetic Support Groups in the UK, 317 Brit. Med. J. 1632 (1998).
[16] Department of Health, 'Committee Announces Decision on Use of genetic test Results for Huntington's Disease by Insurers', see http://www.doh.gov.uk/genetics/gaichuntington.htm
[17] Contrast such specificity of knowledge with general abstract knowledge, such as family history. It is sometimes claimed that a family history is simply genetic information in a different guise, and therefore that a genetic test result is no different to a known family history. Yet, family history is abstract knowledge that has been tainted by bad or failing memories, lack of accurate data about why someone has become ill or died, and by an absence of understanding about the pattern of disease in a family pedigree. In contrast, genetic test results can offer a high degree of specificity, both in terms of predicting the likelihood of disease in other family members and in terms of putting flesh on the bones of a suspicion that has heretofore been unconfirmed. Specific information brings with it a number of realities that can include a degree of "certainty" about future ill-health or even the mode and manner of one's own death. These realities can impact an individual's self-perception in ways that family history cannot, for, with the latter, one has the comfort of having lived with an abstract threat that has always manifested to someone else.

[18] Surely adverse selection concerns do not arise here, because there is no specific knowledge which puts the prospective insured at an advantage over the insurer. And if there is family history, then that would have to be disclosed as a matter of course anyway.
[19] Danish Council of Ethics, 'Ethics and Mapping the Human Genome', 1993 at 60.
[20] Sveger, Thelin & McNeil, 'Neonatal 1-antitrypsin screening: parents' views and reactions 20 years after the identification of the deficiency state' (1999) 88 Acta Paediatrica 315.
[21] Almqvist, Bloch, Brinkman, Craufurd & Hayden, 'A worldwide assessment of the frequency of suicide, suicide attempts, or psychiatric hospitalization after predictive testing for Huntington Disease' (1999) 64 American Journal of Human Genetics 1293.
[22] See, Genetics and Health, supra.
[23] See, Laurie, G.T.; 'Protecting and Promoting Privacy in an Uncertain World: Further Defences of Ignorance and the Right Not to Know', 7(2), European Journal of Health Law, 185-191, 2000, and Laurie, G.T.; 'In Defence of Ignorance: Genetic Information and the Right Not to Know', 6(2), European Journal of Health Law, 119-132, 1999