In Defence of Ignorance

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In Defence of Ignorance: Genetic Information and the Right not to Know

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Introduction

This article considers two concepts which have for a long time received short shrift in the field of medical law and ethics: ignorance and privacy. By 'ignorance' is not meant wilful blindness or lamentable ill-education, but rather, a simple state of no(n)-knowledge. 'Privacy' refers to a state of non-access in which an individual is separate from others and where her interests are paramount. This state of privacy comprises two elements: informational privacy and spatial privacy.

Informational privacy is concerned with the control of personal information and with preventing access to that information by others. Informational privacy is invaded when information is disclosed without authority. This concept is familiar to all of us and is protected, *inter alia*, by legal and ethical duties of confidentiality. Spatial privacy, on the other hand, ensures that the individual herself is in a state of non-access. An obvious example of this is physical separateness from others — physical spatial privacy is invaded when one's physical sphere is invaded — if, for example, we are not permitted to be alone. However, spatial privacy also encompasses separateness of the individual's psyche — and what might be called 'psychological' spatial privacy can be invaded in myriad ways: by someone talking too loudly on the train, by neighbours who fight continuously or by friends who ask impertinent questions. This aspect of spatial privacy protects one's *own* sense of the self. 'Self' is, after all, a psychological construct which is built through the interaction of a number of factors; these may be internal to an individual, such as physiological and genetic make-up or subjective feelings of worth and contentment, or external, such as experiences of other human beings and, indeed, the world generally. Yet external influences incontrovertibly remain outside the control of each of us and at times might

have a deleterious effect on our own sense of 'self'. A realm of psychological spatial privacy permits us to create and retain a greater degree of control over our own concept of who we are and how we choose to engage with the world.

Of course, without qualification this view implies that the very act of engaging with the world may well be seen to be an 'invasion' of privacy, but that is not what is intended here. Rather, the reader is asked to recognise that the act of participating in a community is *sometimes* an assault on our sensibilities and that in *some cases* it is meaningful to say that the assault has gone too far and that an invasion of spatial privacy has occurred. This article explores this thesis using the example of genetics to demonstrate how it can be an invasion of our spatial privacy to receive information about ourselves which we did not previously have and about which we can do nothing. If we accept that an invasion of privacy has occurred in such cases, then we must ask whether it is not better to remain in a state of ignorance. Put another way, should we recognise the value of a right not to know?

The Family as Community in Microcosm

The uniqueness of genetic information lies not so much in its value to individuals as in its ability to alert family members as to their own possible future health status. Thus, genetic test results have implications for family members as well as for the individual who has been tested (the *proband*). On this basis, arguments can be, and have been, made that family members have a right to know the test results of their relatives or that affected individuals have a duty to disclose their status to their 'significant others'[2]. Few of us would deny the strength of the claims of these family members to know the information when a cure exists for the genetic condition in question. Unfortunately, such instances are rare[3], and successful treatments for many conditions remain elusive[4]. The basis of a claim to know then becomes less certain.

Preparedness is often cited as a good reason why information should be disclosed[5], as is the prospect of enhanced reproductive choice[6]; do I really want to procreate if I risk passing on 'defective' genes to my progeny? Such arguments proceed on the assumption, however, that it is always a 'good thing' to know one's own genetic constitution. They seek to provide justifications for removing the control of the information from the proband and placing it in the hands of genetic counsellors and other health care professionals (HCPs) who can 'further' the interests of family members. Here the focus shifts from the welfare of the individual who has been tested to the welfare of the family as a potentially affected community. 'Public' interests intervene to trump

'private' interests, all in the name of the best use of the information. But, as we have seen, opportunities to use this information by way of therapy are rare. Moreover, the harm with which we are concerned in other cases — such as the 'harm' of being ill-prepared or the 'harm' to the choice of procreating — is less easily averted by disclosure and demands for disclosure are, correspondingly, less valid. In addition to this, we cannot assume that the interests of the family community are homogeneous — there is no certainty that all family members would choose to know, given the opportunity. All of these factors should lead us to question the way in which disclosure decisions are taken by genetics counsellors and other HCPs. In particular, it is important that we reflect on the entire range of interests which are at stake and ensure that all relevant factors are weighed in the balance. To illustrate the problems, let us consider a practical example.

Case example

Sophie discovers that she has a genetic form of breast cancer linked to the gene BRCA1[7]. The disorder is dominant and multifactorial. There is a 2 - 3 fold higher instance if a sister is affected, but a clear family history is available in only 10% of cases. Cure is improbable and mastectomy is the most effective preventative measure. Sophie has two sisters, Katie and Sally. Katie is phobic about needles and hates hospitals. Sally is depressive and has recently discovered that she is pregnant. Sophie does not want to tell her sisters about her disease, but should Ivan her doctor do so, even if the knowledge might have adverse implications for their lives?

Justifying Disclosure of Genetic Risk: The Avoidance of Harm?

Why would Ivan disrespect Sophie's wishes and tell the sisters? Arguably, his primary motivation would be to avoid harm and such an aim is, of course, ethically desirable. However, for an action which is designed to avoid harm to be ethically justifiable there must, at least, be a strong likelihood that the harm in question will *de facto* be avoided. In our scenario it is by no means obvious that this would be achieved by disclosing the genetic risk to Sophie's sisters. This is so for each of the three possible harms which could arise — (a) physical harm or death, (b) psychological harm in the guise of unpreparedness, and (c) harm to choice, that is, harm to the facility of being an autonomous individual with a right to choose how to live one's life.

Physical Harm

The nature of the disease with which this case study deals renders the 'treatment option' particularly complex and problematic. A fatal outcome could only be averted by bilateral mastectomy. This, in itself, involves a considerable degree of physical harm through mutilation. Moreover, the measure provides no guarantee of non-recurrence and the adverse emotional consequences of such invasive procedures for women are well-documented and indicate that considerable caution should be exercised before recommending this option[8].

Psychological Harm

Would disclosure facilitate preparedness? Perhaps, but we have no way of knowing whether this would be beneficial to the individuals concerned. Evidence exists which both supports[9] and refutes[10] its benefits. Studies show, for example, that the suicide rate among young Caucasians who know that they carry the Huntington's disease gene is four times as high as the US national average for a comparable, non-affected group[11].

Indeed, we should heed the words of the Danish Council of Bioethics which has warned of the risk of morbidification: the notion of 'falling victim' to some inescapable 'fate' through knowledge about risk of disease[12]. The public have, generally, a misplaced faith in the predictable outcome of genetic knowledge and this makes this problem particularly acute — for the fear of future ill-health may well ruin what turns out to be an otherwise healthy existence. Given the fragile states of both sisters in our scenario, it is more than possible that revelation of the genetic knowledge would exacerbate rather than allay 'psychological harm'. The concern here is not knowledge of one's own death, for we all have that. Rather, it is the supposed 'certainty' surrounding the proximate time and mode of death or ill-health which is disturbing.

Knowledge of death in the abstract is a part of our everyday lives. Knowledge of the specifics of one's own death is an unnatural circumstance and it is one for which we are not necessarily equipped to cope. While it might be argued that an adverse diagnosis given to a patient for *any* condition might provoke the same response, it is important to recognise that the situation is compounded in the context of genetics because information about potential future ill-health can be given to persons who have never had their own health assessed directly and who might not have sought any such assessment. Should such persons thereafter not wish to be tested, they will remain in a state of knowledge-limbo — 'knowing' and yet, at the same time, not knowing their fate.

Harm to Choice

The related question of harm to choice is very complex. For Sophie to tell her sisters that they might possess a gene which could afflict their progeny is to burden them with information which has a direct bearing on all future decisions, including those related to reproduction. What is known cannot then be unknown, and the sisters are now required to reflect on whether they should be tested themselves — and adverse consequences can ensue whatever their decision. If they decide not to be tested then they remain with the uncertainty of ill-health occurring at any time. If they decide to be tested and the test is positive, they find themselves at the beginning of a life-path which is likely to be long and hazardous. But psychological sequelae still remain even if the test result proves to be negative. Huggins et al.[13] and Wexler[14] have carried out studies in families affected by genetic disease and the results show that,

> Many may suffer 'survivor guilt', particularly characteristic of wartime soldiers who live while their buddies are killed[15].

Knowledge forces choices which are not easy and which are not necessarily welcome[16]. We can no longer continue to assume that it is always better to know.

Harm to Reproductive Choice

This is particularly so in the case of Sally who carries a fetus. The additional 'choice' which she faces is that of termination of pregnancy. For her, as for many women, this may not be a choice at all and to disclose the information would, therefore, serve no real purpose. Yet, even if she were not opposed to abortion, the decision to disclose the information at this stage would say much about our attitude towards genetic disease. In essence, the decision to give a pregnant woman knowledge of this sort can only be to facilitate or even encourage an abortion decision. Availability of a prenatal test for a condition for which there is no cure or treatment only allows for a more 'informed' abortion decision. The message given is that non-life is sometimes preferable to life with genetic disease, even though that disease may not manifest itself for many years. In the United Kingdom, the House of Commons Science and Technology Committee found that, in Edinburgh, a prenatal test for the late onset Huntington's disease will not be offered to a woman who is herself afflicted unless she agrees to terminate if the test proves positive[17]. The

rationale is that otherwise the child is burdened by the knowledge of its early death. But why should the future person not have a recognisable interest in not being subject to decisions based on such knowledge, given the substantial number of disease-free years which she or he will enjoy?

A final point on reproductive 'choice' is worth noting. An attempt to justify disrespecting Sophie's 'right' to choose not to reveal the information by reference to the sister's 'right' to make informed reproductive choices is inadequate in itself. As Ngwena and Chadwick have said,

> [i]t is not clear why choice in this area should be given higher priority than choice over the use of personal information...[and] it is not clear that harm to choice itself is sufficiently serious to warrant disclosure[18].

The invasion of Sophie's informational privacy cannot be wholly justified. Furthermore, we risk invading the spatial privacy interests of the sisters by offering them unsolicited information which may actually do them harm.

Respecting Genetic Privacy Interests

Potential harm is not the only reason for claiming an interest in not knowing genetic information. The question of respect also arises. To disclose genetic information to someone who has not expressed a desire to know can be disrespectful in two ways.

First, furnishing an individual with information that she has actually said she does not want to receive disrespects her wishes and is an affront to her as an autonomous person. The pivotal ethical principle of respect for autonomy surely requires that we respect her wishes.

Second, even if no wish has been expressed, we cannot ignore the spatial privacy interests which are also compromised. Giving unwanted information requires the recipient to take into account factors by which she was previously unrestrained, and it coerces her into self-reflection and re-evaluation of her self. Control of information about ourselves must be an essential part of any concept of ourselves as autonomous persons, but 'control' should not be limited merely to control of who has access to that information. It should also include the facility not to accept the information ab initio. A concept of 'control' which is wide enough to encompass this notion permits us to retain a private sphere that is truly our own. Furthermore, it allows us to maintain that unsolicited revelations of personal information is an invasion of that sphere, even when such revelations about ourselves are made to ourselves[19].

The interest in not knowing has been recognised by the Council of Europe

in its *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine*[20], Article 10(2) of which states,

> Everyone is entitled to know any information collected about his or her health. *However, the wishes of individuals not to be so informed shall be observed.* [emphasis added]

Similarly, the UNESCO *Universal Declaration on the Human Genome and Human Rights*[21] states in Article 5c that,

> The right of every individual to decide whether *or not* to be informed of the results of genetic examination and the resulting consequences should be respected. [emphasis added]

It is important to note that privacy can be protected in both the vertical and horizontal planes. The 'human right' of privacy is embodied in a number of international declarations and treaties and is designed to protect, in the first instance, the privacy of the individual vis-a-vis the state (a vertical relationship). In addition to this, the horizontal protection of privacy as between individuals and other persons or institutions is frequently governed at the domestic level by specific privacy laws. The genetic privacy interests with which this article is concerned encompass both vertical and horizontal relations and the ethical content of genetic privacy is the same in each context. However, adequate protection can only come if effective and appropriate legal measures are instituted. It is unfortunate that international instruments such as those quoted above have only marginal effect on domestic legal systems and, in practice, embody little more than 'aspirational rights' — and this has obvious attendant consequences for vertical privacy relations. But, even in the horizontal plane, no means to protect the kinds of genetic privacy interests with which we are concerned — primarily spatial privacy interests in not knowing information — are immediately apparent. What is required is a new concept which allows us to pay due regard to such interests and allows us to accord them adequate legal protection where this is necessary, both in the vertical and the horizontal planes.

The decision to discuss such interests using the language of privacy is deliberate for it is submitted that existing ethical and legal concepts are insufficient to recognise and protect them adequately. Primarily, these 'existing concepts' are autonomy and confidentiality, both of which feature as stalwarts in western medical law and the discipline of bioethics. The remainder of this paper lays out the concerns with these concepts and an

argument is made that a commitment to privacy is the most justifiable and effective protection of the interests which individuals and their relatives have in genetic information.

Confidentiality

Confidentiality arises within a relationship between two or more individuals which imposes a duty on one or more of the parties not to reveal personal information about the other party(ies) without the latter's consent. The paradigm example is the doctor/patient relationship. The application of this concept to the interest in not knowing is problematic for two reasons. First, at least in the United Kingdom, the duty of confidentiality is not absolute and the breadth of its exceptions are ill-defined[22]. In practical terms, this means that confidentiality can be justifiably breached in a whole range of circumstances which are unclear to the subject and when this can undermine the relationship. Furthermore, the perceived claims of family members to know family genetic data would allow a health care professional to breach confidentiality when dealing with sensitive genetic information,[23] but the doctrine itself does not alert the HCP to the possible interests those members might have in not knowing. Similar problems are likely to arise in other jurisdictions, which do not accept an absolute obligation of confidence.

Second, we must bear in mind the true function of the duty of confidentiality, which is concerned primarily with the integrity of the confidential relationship. It is an informational privacy right which ensures that personal information is not disclosed to those outside the relationship. Contrast this with the interest in not knowing which concerns the disclosure of personal information to the subject herself — a spatial privacy right. Confidentiality regulates only the release of information to the outside world, not the internal workings of the relationship. Arguably, however, a health care professional comes under a duty of confidentiality whenever she receives personal health information about another individual[24]. If this is accepted, then a duty is owed to all family members about whom genetic information is known. It is meaningless, however, to suppose that confidentiality is breached by giving someone within the relationship information about herself if it is concerned only with preventing unauthorised disclosure to those outside the relationship. Confidentiality is, therefore, ineffective against intrusions of spatial privacy.

Autonomy

The principle of respect for autonomy focuses on the individual as a 'moral chooser'[25]. The emphasis in medical law and ethics has always been on the need for the provision of information sufficient to allow people to make meaningful choices. Unfortunately, this causes significant problems in the context of the right not to know. In this context, the choice is about 'knowing' in itself: the choice, if there is one, is about whether or not to receive information at all. The fundamental problem with such a 'choice-based" approach has been highlighted by Wertz and Fletcher,

> [t]here is no way...to exercise the choice of not knowing, because in the very process of asking 'Do you want to know whether you are at risk..?'the geneticist has already made the essence of the information known.'[26]

An autonomy/choice approach thus defeats the interest with which we are concerned.

An additional problem raised by autonomy arguments concerns the situation where an individual cannot choose for herself. Various mechanisms are used to enable medical decisions to be taken in such cases, the two most common being the substituted judgement and best interest tests. It is not clear, however, that interests in not knowing are embraced by any such approaches[27]. What is required is a heightening of awareness of the need to recognise and protect such interests and this cannot derive from the concepts either of autonomy or confidentiality.

Privacy

Privacy as defined in this paper permits due recognition to be taken of the interest in not knowing. It acknowledges a sphere of separateness which should not be invaded without justification. An absolute right to privacy is not, however, advocated here. Rather, we look for a prima facie respect which should be accorded unless due cause for disclosure can be shown. A number of factors could be considered when deciding whether or not due cause is present. These include:

— the availability of a cure
— the severity of the condition and the likelihood of onset
— the nature of the genetic disease
— the nature of the testing

— the nature of the request made
— the question of whether disclosure can further a legitimate public interest
— the question of how the individual might be thought to react if exposed to unwarranted information
— the availability of evidence of what the individual would/would not want.

Compare then, a decision to tell a sibling of an affected individual that s/he might be suffering from haemochromatosis — a recessive condition for which there exists an effective therapy (phlebotomy) — and a request from an insurance company or an employer to test for Huntington's disease, for which there is no cure.

In the first case, there is a strong likelihood (25 %) that the relative will be affected, treatment is minimally invasive and effective, and the interest in not knowing is compromised only to the extent that the information is given to secure the strong(er) interest of avoiding physical harm or even death. In contrast, Huntington's disease is a late onset disorder which means that an employee/insured person may be unaffected for many years or even decades. Moreover, the knowledge is burdensome in the extreme given that it means a certain, premature and harrowing death which cannot be avoided. The interest in not knowing is compromised in favour of the primarily financial interest of employers and insurers in knowing. In this latter case, it can be strongly argued that a requirement for genetic testing is an unjustifiable invasion of genetic privacy.

The precise content of the 'right' not to know will be context specific. For example, in the familial milieu, it might include a right not to be given information about a relative's diagnosis or a right not to be required to take part in linkage tests in order to build up an overall family profile. In the context of insurers and employers, it would certainly include a right not to be required to undergo testing and would probably also include a right to resist disclosure of test results if these were required simply to further the interests of third parties. Finally, in the context of a state request for access to genetic information, the right could be used to challenge the legitimacy of, say, a screening programme — for how can population screening be justified if no cure or effective treatment is available for the target condition? Similarly, the right could be used to prevent the state instituting watered-down eugenic policies by surreptitious means. A comprehensive package of pre-natal testing might seem attractive in facilitating reproductive choices, but it can also be used as a means of encouraging the abortion of 'undesirable' fetuses. A right not to know would place the onus on the state to justify such testing; for example, by reference to the health of pregnant women or their fetuses and not by reference to its own social-engineering agenda.

Yet, irrespective of context — and in each case — the kernel of the right not to know is the concept of respect for an individual's privacy interests in not being subjected to unwarranted information about themselves. Thus, while no unitary definition of the right not to know can be offered, the right is, at the same time, sufficiently flexible to protect this underlying interest in wide ranging circumstances.

Giving Effect to Genetic Privacy Rights

There are two ways in which the concept of genetic privacy could play a role in the management of genetic information. First, as an international community, we need to reflect on the reasons why we want to acquire genetic information and on the legitimacy of requests for such information in a number of contexts including requests by family members, by employers and insurers, by the state and requests in the name of 'future persons'. In practical terms, this should translate to an assurance that all health care professionals who are trained to deal with genetic information are made aware of the arguments and the factors which have been advanced in order to determine when, if ever, unsolicited information should be disclosed. Putting the spotlight on genetic privacy forces us to appreciate the true nature of what is at stake.

Second, a specific genetic privacy right could be enshrined both in international instruments and in domestic legislation. Precedents exist for this, at least at the domestic level. In the United States, the federal Genetic Privacy Act[28] was drafted in 1995 with the aim of ensuring that no stranger should have or control identifiable genetic information about an individual without the individual's consent. Although the Act takes an autonomy-based approach to privacy in that it focuses on the need for consent, genetic (spatial) privacy interests are recognised indirectly. For example, the Act provides that minors shall not be tested for any condition which manifests itself after the age of 16 unless an effective intervention can be made before 16. Similarly, a test for other conditions which do afflict minors shall only be permitted if an effective intervention before the age of 16 will delay the onset of and/or ameliorate the severity of the disease. It is submitted that this is a recognition of the child's spatial privacy interests and represents an attempt to protect them against unjustifiable disclosure. It is interesting, and arguably correct, that the 'right' of the minor in this context is not absolute and that intervention is possible where actual physical harm can be minimised or avoided. Legislation along these lines could extend the protection of genetic privacy to others, ensuring that testing would be permissible only in the most justifiable

of circumstances — probably only when physical harm to the subject could be avoided.

By March 1998, sixteen American states had introduced laws regulating the privacy of genetic information and some 150 bills had been proposed in state legislatures[29]. New Jersey has passed a Genetic Privacy Act modelled significantly on that discussed above. A number of bills were pending in the 105th session of Congress including the Genetic Confidentiality and Non-Discrimination Act 1997 and the Genetic Privacy and Non-discrimination Act 1997, both of which aim to protect individual and familial DNA samples from unwarranted access to and control by third parties. Many valuable lessons will undoubtedly be learned from the American experience.

Conclusion

While there is no volonté within the European Community equivalent to that in the US to legislate on genetic privacy at the present time, the Council of Europe Convention deals specifically with genetic issues and urges the establishment of certain key base-lines in all signatory countries[30]. Among these, as we have seen, is the express recognition of an interest in not knowing information. Thus, we find ourselves at the beginning of a new era in bioethics, one which requires us to open ourselves to a more nuanced approach to the treatment of information generally — and genetic information more particularly.

This paper has offered some tentative suggestions as to how we might proceed in this relatively uncharted area. Yet, while a defence has been mounted of the right not to know which is premised on the view that inaction and ignorance can sometimes be acceptable, it is imperative that we do not apply such a philosophy to the response of the discipline of medical law and ethics to advances in genetics. For this task, we cannot simply rest on our laurels and rely on the adage that ignorance is bliss. We need to familiarise ourselves with all the options and to avail ourselves of those which best reflect and best protect the entire range of interests which are in issue[31].

Notes:

1. The ideas contained in this paper form the basis of a monograph entitled *Legal and Ethical Aspects of Genetic Privacy* to be published by Cambridge University Press in 2000.
2. See, English, V. and Sommerville, A.; 'Genetic Privacy: Orthodoxy or Oxymoron?', 25, Journal of Medical Ethics, 144, 1999. Also, Pelias, M.Z.; 'Duty to Disclose in Medical Genetics: A Legal Perspective', 39, *American Journal of Medical Genetics*, 347, 1991.

3. While 95% of the most common genetic diseases can now be tested for, the number of available cures remains lamentably low.
4. As the United Kingdom's House of Commons Science and Technology Committee pointed out: 'While genetics is likely eventually to transform medicine, it may take some while before treatments based on genetic knowledge become available...[i]n the short term, the most widespread use of medical genetics will be, as now, in diagnosis and screening.', see — House of Common Science and Technology Committee *Human Genetics: The Science and its Consequences* Third Report HMSO, 6 July 1995, at 36 - 37, paragraphs 71, 72.
5. Ball, D., Tyler, A. and Harper, P.; 'Predictive Testing of Adults and Children' in Clarke, A. (ed.), '*Genetic Counselling: Practice and Principles*', London, Routledge, 1994, at 63 - 94, especially at 71.
6. Malinowski, M.J.; 'Coming into Being: Law, Ethics and the Practice of Prenatal Genetic Screening', 45(6), *Hastings Law Journal*, 1435 - 1526, 1994. Cf, Botkin, J.R.; 'Fetal Privacy and Confidentiality', 25(5), Hastings Center Report, 32 - 39, 1995.
7. The gene is thought to be responsible for around five percent of all breast cancers. For a statistical analysis and comment see, Eeles, R.; 'Testing for the Breast Cancer Predisposition BRCA1', 313, *British Medical Journal*, 572, 1996.
8. Struewing et al.; 'Prophylactic Oophrorectomy in Inherited Breast/Ovarian Cancer Families', 17, *Journal of the National Cancer Center Monographs*, 33-35, 1995, and Stefanek, M.E.; 'Bilateral Prophylactic Mastectomy: Issues and Concerns' 17, *Journal of the National Cancer Center Monographs*, 37 - 42, 1995.
9. Hayden, M.R.; 'Predictive Testing for Huntington's Disease: Are we Ready for Widespread Community Implementation?', 40, *American Journal of Medical Genetics*, 515, and Brandt, J. et al.; 'Presymptomatic Diagnosis of Delayed-Onset with Linked DNA Markers: the Experience with Huntington's Disease', 261, *Journal of the American Medical Association*, 3108, 1989.
10. Kevles, D.; 'In the Name of Eugenics: Genetics and the Uses of Human Heredity', London, Penguin Books, 1985 at 298, Andrews, L.; 'Legal Aspects of Genetic Information', 64, *The Yale Journal of Biology and Medicine*, 29, 1990 and Craufurd, D. et al.; 'Uptake of Presymptomatic Predictive Testing for Huntington's Disease', 2, *The Lancet*, 603, 1989.
11. Andrews, *loc. cit.*
12. Danish Council of Ethics, *Ethics and Mapping the Human Genome*, 1993 at 60.
13. Huggins, M. et al.; 'Predictive Testing for Huntington's Disease in Canada: Adverse Effects and Unexpected Results in Those Receiving a Decreased Risk', 42, *American Journal of Medical Genetics*, 508, 1992.
14. Wexler, N.; 'Genetic Jeopardy and the New Clairvoyance', 6, *Progress in Medical Genetics*, 277, 1985.
15. ibid.
16. Husted has argued that choices in such circumstances are not autonomous choices since they are 'forced' by the giving of unsolicited information, see Husted, J.; 'Autonomy and a Right Not to Know' in Chadwick, R., Levitt, M. and Shickle, D. (eds.); '*The Right to Know and the Right Not to Know*', Aldershot, Avebury, 1997, chapter 6.
17. House of Commons Science and Technology Committee, '*Human Genetics: The Science and its Consequences*', Third Report, London, HMSO, July 1995, at paragraph 90.
18. Ngwena, C. and Chadwick, R.; 'Genetic Diagnostic Information and the Duty of Confidentiality: Ethics and Law', 1, *Medical Law International*, 73, 1993, at 86.
19. See further, Laurie, G.T.; 'The Most Personal Information of All: An Appraisal of Genetic Privacy in the Shadow of the Human Genome Project', 10, *International Journal of Law, Policy and the Family*, 74, 1996.
20. Council of Europe, *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on*

Human Rights and Medicine, Oviedo, April 1997.

21. Adopted unanimously on 11 November 1997 in Paris at the Organisation's 29th General Conference.
22. See, Lesser, H. and Pickup, Z.; 'Law, Ethics and Confidentiality', 17, *Journal of Law and Society*, 17, 1990.
23. Laurie, *loc. cit.*, at 79 - 87.
24. This is certainly true in the United Kingdom, see *Attorney General v Guardian Newspapers No.2* [1990] 1 AC 109, HL.
25. This expression is borrowed from Stanley Benn. He uses it, *inter alia,* in his work '*A Theory of Freedom*', Cambridge, Cambridge University Press, 1988.
26. Wertz, D.C. and Fletcher, J.C.; 'Privacy and Disclosure in Medical Genetics Examined in an Ethic of Care', 5, *Bioethics*, 212, 1991, at 221.
27. In the United Kingdom the Law Commission and the Scottish Law Commission have both reported on the law relating to incapaces and have offered revised legal models on how to treat such persons in their own best interests. In neither report is there any significant appreciation of privacy interests which are sensitive to an interest not to know, see Law Commission, *Mental Incapacity,* No 231, 1995; Scottish Law Commission, *Report on Incapable Adults*, No 151, 1995.
28. For comment see, Lin, M.M.J.; 'Conferring a Federal Property Right in Genetic Material: Stepping into the Future with the Genetic Privacy Act', 22, *American Journal of Law and Medicine*, 109, 1996.
29. *The Gene Letter,* volume 2, Issue, 2, March 1998.
30. Note 20 above, and text.
31. Sincere thanks are due to Professor JK Mason of the University of Edinburgh for his invaluable comments on an earlier draft of this article. All responsibility for the contents of this work rests solely with the author.