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### Genetic Information and the Challenge to Privacy

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#### Introduction

When Watson and Crick unravelled the structure of DNA they paved the way for tremendous advances in science and medicine. [1] That discovery has facilitated the development of diagnostic tests which can predict the likelihood of suffering from certain diseases. It has enabled scientists to investigate new ways of producing drugs and treatments. However, all scientific advances carry potentially detrimental consequences and this is as true of the new genetic technologies as it is of nuclear power or the internal combustion engine. Currently the most dramatic progress in genetics has been the development of tests which generate predictive information about the likely health status of individuals. However, as Epstein points out:

“The possibility that genetic information may be used at all creates the possibility that it may be used badly. The long history of the eugenics movement is evidence that the mere possession of information gives no assurance that it will be used for wise ends.” [2]

This paper highlights some of the problems likely to arise through the use of genetic technology to obtain information about individuals.

#### The problems of genetic information

The Sunday Times recently carried the story of a 29 year old man whose mortgage application had been rejected following a motorcycle accident. [3] During emergency surgery doctors noticed some small cysts on his kidneys which indicated that he was suffering from the early stages of a genetic disorder known as polycystic kidney disease. This information was entered on his medical records and the burden of the article was that his genetic composition had led the financiers to the conclusion that he was a bad risk for a mortgage loan. Incidents such as this have led to calls for some form of legislation to protect the privacy of genetic information. In the United States the Human Genome Project's Ethical, Legal and Social Implications programme has recently produced a draft Genetic Privacy Act. [4] Efforts have been made in some individual states, so far unsuccessfully, to introduce the provisions of this statute into state law. [5]

In the United Kingdom the House of Commons Select Committee on Science and Technology recommended in its 1995 report [6] that the Privacy Bill proposed by the National Heritage Committee [7] should be utilised to protect the privacy of genetic information. In particular, the Select Committee recommended that “misuse of genetic information should be both a criminal and civil offence.” This paper considers the scope and function of privacy protection in relation to genetic information.

#### The Need for a Privacy Law

A first step in determining the need for privacy protection for genetic information is to ascertain what, if any, societal difficulties such a law would address? In the growing literature on this topic there would appear to be three particular areas of concern in relation to private genetic information. First, there are problems related to the provision and purchase of life and health insurance; secondly there are problems relating to the possibility of employment discrimination; and finally there is the possibility of familial conflict arising from demands to share sensitive information pertaining to genetic health.

## Insurance

Increasingly large areas of our public and private lives have become influenced by the need for insurance. In the United Kingdom, it is just still possible to avoid the need for health insurance, but this is certainly not the case in the United States where an estimated 35 million people are currently without health care cover. [8] Life insurance has effectively become a prerequisite for the purchase of property. Private sector insurers have an economic interest in acquiring as much information as possible about the future health care status of an individual. This is done, according to the insurance industry, to minimise the possibility of adverse selection. The insurance companies claim that they incurred heavy financial losses in the early years of the HIV/AIDS epidemic because individuals were adversely selecting insurance policies. [9] Adverse selection occurred when those who discovered that they were HIV positive and therefore likely to require a greater degree of health insurance cover, purchased more insurance than would be normal. Since insurance companies calculate premiums on the basis that a large number of the individuals insured will not draw on their pooled resources, any deviation from the projected figures will severely curtail profits. Insurance companies fear that the adverse selection which allegedly damaged them in the 1980s will be repeated on a larger scale in the future as individuals procure an indication of their life span through predictive genetic tests. It is only fair, argue the insurance companies, that they should be allowed to request this information. Indeed, following numerous international reports on this issue there has been a remarkable degree of homogeneity in the response of the insurance industry to genetic testing. The industry argues that they do not have an interest in insisting that such tests be carried out but rather are more concerned with the need to have access to the results of any tests which have been carried out. [10] This is in keeping with the classic position of *uberimmae fides* which has prevailed in the insurance industry since its creation. [11]

Following the concerns raised by the Select Committee on Science and Technology in 1995 the United Kingdom government established the Human Genetics Advisory Committee to oversee developments in this area. The Commission identified the insurance issue as one of the priority areas of its work and published a report on *The Implications of Genetic Testing for Insurance* in 1997. [12] The report recommended that the insurance industry should respect a moratorium on requiring disclosure of results of genetic test results. [13]

## Employment

The second difficulty which has added to the demands for some form of privacy protection for genetic information lies in the possibility of employment discrimination based on genotype. Although the technology for genetically testing and screening employees is not yet perfected, studies have already documented a significant number of cases of genetic discrimination in employment. [14] There is some debate about whether selecting individuals according to genotype amounts, in fact, to discrimination, given that it does not *prima facie* offend against Aristotelian notions of treating like as like. However, the possibility of scientific error is significant enough to raise concerns about the possibility of individuals being wrongly classified as genetically at risk. Allegations of discrimination based on perceived genotype has been most prevalent in the United States where a large proportion of American people receive their health insurance cover as a secondary benefit of their employment. Employers are, consequently, keen to lower their insurance costs by attempting to select only those employees who are likely to remain in good health. One means of making such a selection is to screen the workforce in order to determine who is susceptible to genetic disease or, perhaps more importantly (given the longer term health care costs), for those who are likely to have children who will suffer from a genetic disorder. [15]

## Information

A third area of difficulty which has led to calls for a genetic privacy law is that of genetic information disputes arising between individuals. This has commonly been characterised as the "right to know debate". [16] Given the nature of genetic information, situations can arise where a genetic test result for one individual will also

have a significant impact on his or her siblings and wider family circle. [17] Often there will be no difficulty and the information in question will be passed on. However, there may be many reasons, rational and irrational, why individuals will not want to share the results of their genetic diagnosis. It is this situation which has, at least in part, given rise to the question of whether individuals should have the right to know the results of a third party genetic test in order to make significant future life decisions for themselves. Equally there will be those who, aware of the potential financial, social and emotional difficulties that such a diagnosis can carry, will have no desire to learn the results of a genetic diagnosis. These individuals argue that they have a right not to know information which has a direct or indirect reference to their genetic health. [18]

### **A Privacy Law Remedy?**

The claim that a genetic privacy law could provide a remedy for the problems outlined above is not uncontentious, not least because there seems to be no particular consensus on the nature or content of the concept of privacy. Difficulties of definition are exacerbated by the fact that there is a significant divergence between the European concept of privacy, which places great emphasis on the need to protect human dignity, and the Anglo-American tradition which concerns itself, as Gostin describes, with the "right of individuals to limit access by others to some part of their persons." [19] It has been suggested by some commentators that the (American) modern legal formulations of privacy can be utilised and developed to provide remedies for disputes about genetic information. There are a number of problems with this line of reasoning. First, it is not entirely straightforward that a "right to be let alone" [20] can be interpreted in order to resolve arguments about whether there is a right to know or not to know private genetic information. [21] Privacy is often spoken of as if it were, in itself, an absolute and fundamental human right. It may, however, be a concept which does not possess a sufficiently deep ethical foundation to justify such a privileged position in the hierarchy of rights. A further problem is that there appears to be no particular consensus about the precise objective of privacy laws. On the one hand it is argued by proponents of genetic privacy legislation that these measures will prevent the worst excesses of genetic discrimination. Alternately, it has been argued by others that concentrating on the need for procedural safeguards to prevent the dissemination of private genetic information does nothing to strike at the deeper problems of genetic discrimination. [22]

### **The ELSI Genetic Privacy Act**

Under the Human Genome Project a significant proportion of the funding has been channelled into research into the ethical, legal and social implications of genetic technology. This work which takes place under the umbrella of the ELSI group has led a team of researchers to develop a Genetic Privacy Act. In their commentary to the draft legislation the authors outline the objectives of the proposed legislation:

"the overarching premise of the Act is that no stranger should have or control identifiable DNA samples or genetic information about an individual unless that individual specifically authorises the collection of DNA samples for the purpose of genetic analysis, authorises the creation of genetic information, and has access to, and control over the dissemination of that information."

The legislation is structured in terms of researcher/clinician obligations and patient or sample source rights. Under the Act any person who screens an individual or who collects a DNA sample must verbally provide specific information prior to collection of the DNA sample. [23] Secondly, he or she must provide the patient with a notice of rights and assurances prior to the collection of the DNA sample. [24] Thirdly, there is an obligation to obtain written authorisation for the screening or testing [25] and to restrict access to the samples to those persons who are authorised by the screened or tested person. [26] Finally, the person collecting the DNA must abide by the sample source's instruction in relation to the maintenance [27] and destruction of DNA samples. [28]

In addition to the obligations placed on the clinician the sample source has certain rights explicitly set out in the Act. Thus he or she can determine who may collect and analyse DNA. The sample source can determine the purposes for which a sample can be analysed and have the right to know what information can reasonably be expected to be derived from the analysis. [29] The sample source has the right to order its destruction and to delegate this authority to a third party after death. [30] The source also has the right to refuse permission for the sample to be used for commercial or research activities and to obtain copies of any records which emerge from the analysis. [31]

However, the legislation contains a large number of exceptions to the overarching principle of privacy set out by the drafters. Genetic information can be disclosed for use in a law enforcement proceeding in which the person holding the information is the subject of the proceedings. [32] In addition, disclosure of genetic material is permissible where it is needed for identification in law enforcement proceedings. The Act also contains provision for the issuance of a court order to compel the disclosure of private genetic information where:

- “(1) other ways of obtaining the private genetic information are not available or would not be effective; and
- (2) there is a compelling need for the private genetic information which outweighs the potential harm to the privacy interest of the subject of the information.” [33]

Genetic information may also be used for research purposes provided that a research ethics committee has given its approval. [34] The issue of the right to know is explicitly considered in s. 133 of the Act which states that where:

“ a relative of a deceased sample source is at risk of a genetic disease which in reasonable medical judgment could be effectively ameliorated, prevented or treated, nothing in this Act shall be construed as prohibiting researchers from contacting such relatives and informing them of the risk.”

The legislation also permits the taking of samples from children [35] and incompetent persons. [36] In the case of incompetent persons the analysis must be necessary to diagnose the cause of incompetence and any information so obtained can be disclosed where necessary for the diagnosis of a proven genetic condition. [37]

### **European Privacy Directive 95/46**

Directive 95/46 was adopted by the Council in July 1995. [38] The full title of the legislation is “Directive on the protection of individuals with regard to the processing of personal data and on the free movement of such data.” This convoluted formulation reflected the attempt which is made by the legislation to strike a balance between ensuring that there is as free a flow of personal data information as would be consistent with the objectives of the free market alongwith ensuring the maximum data protection for individuals. Again this compromise approach is reflected in Art 1 of the Directive which states that:

- “1. In accordance with this Directive, Member States shall protect the fundamental rights and freedoms of natural persons, and in particular their right to privacy with respect to the processing of personal data.
- 2. Member States shall neither restrict nor prohibit the free flow of personal data between Member States for reasons connected with the protection afforded under paragraph 1.”

The directive may well have an impact on decisions relating to genetic information under Article 8 which states that:

- “1. Member states shall prohibit the processing of personal data revealing racial or ethnic origin, political opinions, religious or political beliefs, trade union membership, and the processing of data relating to health or sex life.”

The directive does, however, predictably provide a number of exceptions to the fairly strict prohibition contained in Article 8. Thus the rule does not apply where the “data subject” has given explicit consent, [39] where the data processing is necessary under the provisions of employment law, [40] where the data must be processed to protect the vital interests of a person who is physically or legally incapable of giving consent. [41] Perhaps most significantly from the perspective of genetic information Article 8 (3) provides that:

“Paragraph 1 shall not apply where processing of the data is required for the purposes of preventive medicine, medical diagnosis, the provision of care or treatment or the management of health-care services, and where those data are processed by a health professional subject under national law or rules established by national competent bodies to the obligation of professional secrecy or by another person also subject to an equivalent obligation.”

As Callens points out the Directive only applies to “personal data” [42] which is defined in Article 2 of the Directive as:

“any information related to an identified or identifiable natural person; an identifiable person is one who can be identified, directly or indirectly, by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity.”

The Directive also provides the “data subject” with a number of positive rights, including the right to be informed about the processing of personal data, the right of access to the data and the right to object to the processing of the data. The individual has the right to be informed who the data controller is, the purposes for which the information is being processed, of the existence of a right of access to the data and the right to rectify any inaccuracies in the data. [43] A similar group of rights exist under Article 11 when the information has been obtained from someone other than the data subject themselves. Article 12 details the rights of access of the data subject to the information held by the data controller.

These rights seem *prima facie* to present a reasonable package likely to alleviate the concerns many people may have in relation to the collection and use of genetic information. However, even these rights cannot be considered absolute. Article 13 contains a series of exemptions and restrictions to the rights contained *inter alia* in Articles 10, 11 and 12. These exemptions to the data subject rights outlined above will apply where the restriction constitutes a measure necessary by reason of: national security, defence, public security, prevention, investigation and detection of criminal offences or of breaches of ethics for regulated professions; the protection of the data subject or the rights and freedoms of others.

### European Convention on Bioethics and Biomedicine

Alongside the Privacy Directive a further development in European genetic jurisprudence is the recent enactment of the European Convention on Bioethics and Biomedicine. The completion of the European Convention on Human Rights and Biomedicine, finally agreed by the Committee of Ministers of the Council of Europe in November 1996 [44] represents a significant development in the regulation of genetic technology in Europe. [45] The Parliamentary Assembly of the Council of Europe began work on a draft Convention on Bioethics in 1991. After a protracted and controversial discussion period the Convention was endorsed by all but three of the thirty nine participating nations in 1996 and was finally signed by five of the participating nations at a special ceremony in Oviedo in April 1997. [46] The Convention marks a significant attempt to address the problems of bioethics through the use of a human rights framework. [47] Although not solely concerned with the issues of genetic screening, a complete section of the document is devoted to the human genome. Article 12 explicitly addresses the question of genetic screening stating that:

“Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to disease may be performed only for health purposes or for scientific research purposes, and subject to appropriate genetic counselling.” [48]

As is often the case with international human rights documents the language used in this Article is somewhat open. The restriction of genetic diagnostics to “health purposes” and “scientific research purposes” clearly has implications for those who would seek to use genetic screening in the workplace or in the determination of life and health insurance premiums. The meaning of the provision can be elucidated further by reading the provisions of Art 11 in conjunction with those of Art 12 which states that:

“Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.” [49]

This provision attempts to address the much discussed difficulties expected to arise from the use of predictive genetic testing in the areas of employment and insurance. [50] Concerns that the provisions of the Convention will have a significant impact on such matters has prompted bodies such as the Association of British Insurers to publicly denounce certain aspects of the Convention claiming, for example, that Article 11, prohibiting discrimination on genetic grounds, was unenforceable. [51]

Articles 11 and 12 suggest that genetic testing carried out in the workplace may only be acceptable where it is performed for the health benefit of the employee. Consequently the use of such diagnostic techniques to

exclude from work those with a predisposition to ill health may well be prohibited. This would be in keeping with the approach adopted in many of the nation states which contributed to the discussion of the Convention. Similarly, articles 11 and 12 would seem to suggest that genetic screening for the purpose of obtaining insurance will also be unacceptable. One key point not directly addressed in the Convention is whether individuals who have had a genetic test "for health purposes" or any other purpose will be required to disclose the results of that test to an insurance company. One of the central tenets of insurance underwriting is symmetry of information; this is the idea that the insurance policy taker should disclose whatever relevant information he or she possesses to the insurance company. In a situation where there is asymmetry of information the possibility of adverse selection arises. Such concerns explain, although do not necessarily fully justify, the insurance industry demands that they be permitted to request disclosure of results of genetic tests which have already been performed.

However, insurance companies have also argued that they should be allowed to request or require policy takers to submit to genetic testing. [52] The major protection insurers have against adverse selection is the requirement that all contracts must be made *uberimmae fides*. If a policyholder does not act in the utmost good faith by disclosing all material information then the insurance contract is voidable. However it is clear that these central principles of insurance do not necessarily provide a basis for demands that individuals be required to undergo genetic testing before being accepted for insurance. Where an individual is unaware of his or her genetic profile there is no asymmetry of information because the putative policy holder is as ignorant of their genetic status as the insurance company. In such a situation there is no risk of adverse selection and consequently no need to compel testing and disclosure.

Two key points emerge from this analysis. The first is that the insurance industry is being somewhat disingenuous when it offers, as the ABI has done in a recent policy statement, not to require genetic testing before offering insurance. [53] The ABI stated that:

"It is important that insurance companies continue to see the results of genetic tests so they can monitor developments and gauge any impact on their company. However, the industry will not ask anyone to take a genetic test when applying for insurance"

Such a requirement would not be warranted according to the principles on which the industry itself operates. The rationale for disclosure of the results of any form of medical test is based on the concepts of symmetry of information and the doctrine of *uberimmae fides*. The argument that results must be disclosed in order to enable companies to monitor developments cannot be based on these central insurance concepts. The argument for such requirements, while perhaps economically sound, marks a departure from the traditional arguments of the insurance industry. The second point is that legislation which seeks to prevent insurance companies from requesting the carrying out of tests is both disproportionate and unnecessary. Better to have such laws than not, some might say. However, this ignores the fact that such legislation may have a number of negative consequences. Legislation which limits the use of genetic testing in areas where it is not necessary to do so may well have the effect of "chilling" pharmaceutical companies and biotechnology researchers from developing and marketing genetic tests. If the genetic tests are not available then it is possible that this will severely curb efforts to develop effective gene therapy techniques.

Article 11 of the Convention prohibits any form of discrimination based on genetic heritage. This loosely worded provision raises interesting questions of whether gender or sexual orientation can be considered part of genetic heritage. It also threatens to impact upon another major feature of modern underwriting insofar as it may apply to the practice of differentiating between different risks. This practice is also based around notions of equity and actuarial fairness which hold that those who bring a higher risk to the mutual fund should pay a higher premium. [54] In one sense the insurer is clearly required to discriminate between different individuals. Where the relevant risk information is based on the results of a previously taken genetic test then it would seem that the insurance company would be discriminating against a person on the basis of his or her genetic heritage and may well be in violation of Article 11. On the other hand, if the insurance companies are permitted to use the information and it becomes apparent that certain societal disbenefits arise as a consequence then the willingness of the public to take up genetic tests may be adversely affected. [55]

## Conclusion

Currently, the major threat posed by genetic information to the individual is that personal data may be used to deny opportunities and facilities which are regarded as essential in a modern society. The question arises as to whether this makes genetic information qualitatively different from other medical information. This is a complex issue but at the very least genetic information can be singled out for particular concern because of its particular predictive power. Unscrupulous use of such information could lead to the denial of employment, of

mortgages, pensions, loans and of life and health insurance. While legislation which protected genetic privacy could diminish the impact of such practices it can only ever be partially successful. The introduction of privacy laws might just as readily erode our sense of social solidarity by encouraging individuals to hide information which it is in the broader public interest to share. A more appropriate legislative response to the difficulties posed by the uncovering of large quantities of predictive genetic information is to foster a climate where there is no particular need to conceal this information, because no detrimental consequences will flow from its revelation. This might best be achieved by the introduction of laws which are targeted at the use and misuse of genetic information rather than the collection and storage of it.

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## End Notes

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3. "Health checks that carry a high risk" The Sunday Times 21 July 1996.
4. Annas, GJ., Glantz, LH., Roche, PA The Genetic Privacy Act and Commentary Boston University School of Public Health (1995). Available at <http://www-bushph.bu.edu/Depts/HealthLaw/>.
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10. Nuffield Council on Bioethics Genetic Screening: Legal and Ethical Issues (1993).
11. Marine Insurance Act 1906. s.17 " A contract of marine insurance is a contract based upon the utmost good faith, and, if the utmost good faith be not observed by either party, the contract may be avoided by the other party." s.18(2) "Every circumstance is material which would influence the judgment of a prudent insurer in fixing the premium, or determining whether he will take the risk." s.20(1) "Every material representation made by the assured .. to the insurer during the negotiations for the contract and before the contract is concluded must be true. If it be untrue the insurer may avoid the contract" The concept of *uberimmae fides* upon which so much of the insurance industry is based was succinctly stated in *Carter v Boehm* [1905] "Insurance is a contract upon speculation. The special facts, upon which the contingent chance is to be computed, lie most commonly in the knowledge of the insured only: the underwriter trusts to his representation, and proceeds upon confidence that he does not keep back any circumstance in his knowledge, to mislead the underwriter into a belief that the circumstance does not exist, and to induce him to accept the risque, as if it did not exist. The keeping back of such circumstances is a fraud and therefore the policy is void."
12. Human Genetics Advisory Commission The Implications of Genetic Testing (1997).
13. *ibid* para 6.10.
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15. see generally National Human Genome Research Institute Genetic Information and the Workplace January 1998. Available at [http://www.nhgri.Hih.gov:80/HGP/Reports/genetics\\_workplace.html](http://www.nhgri.Hih.gov:80/HGP/Reports/genetics_workplace.html).
16. see generally Chadwick, R., Shickle, D., Leavitt, M. (Eds) *The Right to Know and the Right Not to Know* Avebury Press. (1997).
17. Ngwena, C., Chadwick, R "Genetic diagnostic information and the duty of confidentiality: Ethics and law." 1 *Medical Law International* 73 (1993).
18. Suter, SM "Whose genes are these anyway? Familial conflict over access to genetic information" 91

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19. Gostin, L "Health Information Privacy" 80 Cornell Law Review 451 (1995).
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  22. Parmet, WE "Legislating privacy: The HIV experience" 23 Journal of Law, Medicine and Ethics 371 (1995).
  23. s.101(b) "Prior to the collection of a DNA sample from a sample source for genetic analysis, the person collecting the sample or causing the sample to be collected shall verbally inform the sample source or the sample source's representative."
  24. s.105 "A person who collects or stores DNA samples for genetic analysis shall provide a sample source or a sample source's representative prior to the collection, storage or analysis of a DNA sample, and any other person upon request, with a notice of rights and assurances."
  25. s.101(a) "no person may collect or cause to be collected an individually identifiable DNA sample for genetic analysis without the written authorisation of the sample source or the sample source's representative."
  26. s. 112. This section establishes a series of requirements to be met before an authorisation for disclosure of private genetic information will be considered valid.
  27. s.102 "genetic analysis of an individually identifiable DNA sample is prohibited unless specifically authorised in writing by the sample source or the sample source's relative."
  28. s.104(c) "An individually identifiable DNA sample must be destroyed on completion of genetic analysis unless:  
(1) the sample source or the sample source's representative, has directed otherwise in writing, or  
(2) all individual identifiers linking the sample to the sample source are destroyed."
  29. s.103(a) (2) - (6).
  30. s.104(b) "the sample source or the sample source's representative shall have the right to order the destruction of the DNA sample."
  31. s.103(8).
  32. s.115 (a) "No person who maintains private genetic information may be compelled to disclose such information pursuant to a request for compulsory disclosure in any judicial, legislative or administrative proceeding, unless:.. (3) The genetic information is for use in a law enforcement proceeding or investigation in which the person maintaining the information is the subject or party."
  33. s.115(d).
  34. s.132 (a) "Any person who, in the ordinary course of business, practice of a profession, or rendering of a service, stores or maintains private genetic information is prohibited from allowing access to such information to researchers unless:  
(1) an Institutional Review Board has approved the conduct of the research program or study; and;  
(2) the sample source or the sample source's representative has specifically consented to the access or disclosure of such information in an authorisation that meets the requirements of s.112."
  35. ss 141 and 142.
  36. s.143.
  37. s.144.
  38. European Privacy Directive 95/46 OJ No C 93/3 April 13th 1995.
  39. Article 8 (2) (a) Privacy Directive 95/46.
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  42. Callens, S "The Privacy Directive and the Use of Medical Data for Research Purposes" 2 European Journal of Health Law 309 (1996).
  43. Article 10 (a) - (c) Privacy Directive 95/46.
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  45. 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 Biomedicine* 164

- European Treaty Series. Oveido. (1997).
46. "Council of Europe announces signature date for Bioethics Convention" Eurowatch 21 March 1997
  47. For a critique of this approach see Iles, AT "The Human Genome Project: A Challenge to the Human Rights Framework" 9 Harvard Human Rights Journal 27 (1996).
  48. Article 12 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 Biomedicine.
  49. *ibid* Article 11.
  50. see, for example, Rothstein, MA "Discrimination based on genetic information" 33 *Jurimetrics Journal* 13 (1991); Matthewman, WD "Title VII and genetic screening: can your genes screen you out of a job?" 27 *Howard Law Journal* 1185 (1984); Smith, GP., Burns, TJ "Genetic determinism or genetic discrimination" 11 *Journal of Contemporary Health Law & Policy* 23 (1994); Kupfer, J "The ethics of genetic screening in the workplace" 3 *Business Ethics Quarterly* 17 (1993); Jaeger, A. "An insurance view on genetic testing" 8 *Forum for Applied Research and Public Policy* 23 (1993); Resnik, DB "Genetic privacy in employment" 7 *Public Affairs Quarterly* 47 (1993); Rothstein, MA., Knoppers, BM "Legal aspects of genetics, work and insurance in North America" 3 *European Journal of Health Law* 143 (1996); Gevers, S "Use of genetic data, employment and insurance: An international perspective" 7 *Bioethics* 126 (1993).
  51. Eurowatch 21 March 1997.
  52. For a fuller argument on this point see Sandberg, P "Genetic information and life insurance: a proposal for an ethical European policy" 40 *Social Science & Medicine* 1549 (1995).
  53. "ABI issues policy statement on life insurance and genetics" Press Release 18 February 1997 available at <http://www.abi.org.uk/>.
  54. For an argument against actuarial fairness as fairness see Daniels, N "Insurability and the HIV epidemic: ethical issues in underwriting" 68 *Milbank Quarterly* 497 (1990); see also Murray, TH "Genetics and the moral mission of health insurance." Murray questions whether it is appropriate to apply a principle developed to differentiate between different risks in the context of shipping to human beings.
  55. There is an extensive literature relating to the use of genetic tests in insurance. See, for example, O'Hara, S. "The Hastings Center Report" 12 (1992); Pokorski, RJ "Insurance underwriting in the genetic era" 60 *American Journal of Human Genetics* 205 (1997); Alper, JS., Natowicz, M "Genetic Testing and Insurance" 307 *BMJ* 1506 (1993); Dickson, D "Insurance companies fight for rights to genetic data" 365 *Nature* 198 (1993); Gevers, S "Use of Genetic Data, Employment and Insurance: An international Perspective" 7 (2) *Bioethics* 126 (1993); Jecker, NS "Genetic Testing and the Social Responsibility of Private Health Insurance Companies" 21 *The Journal of Law, Medicine and Ethics* 109 (1993); McEwen, JE., McCarty, K., Reilly, P "A survey of medical directors of life insurance companies concerning use of genetic information" 53 *Am J Hum Genet.* 33 (1993); Miller, JM. "Genetic testing and insurance classification: National action can prevent discrimination based on the 'luck of the genetic draw'" 93 *Dickinson Law Review* 729 (1989); Oster, H., Allen, W., Crandell, LA., Moseley, R., Dewar, M., Nye, D., McCrary, SV. "Insurance and Genetic Testing: Where are we now?" 52 *American Journal of Human Genetics* 565 (1993); Rothenburg, KH "Genetic Information and Health Insurance: State Legislative Approaches" 23 *Journal of Law, Medicine and Ethics* 312 (1995); Rothstein, MA ., Knoppers, BM "Legal Aspects of Genetics, Work and Insurance in North America and Europe" 3 *European Journal of Health Law* 143 (1996). For an insurance industry perspective see Leigh, S "The Freedom to Underwrite" Occasional Paper. Institute of Actuaries. London (1996); Jaeger, AS "An Insurance View of Genetic Testing" 8 *Forum for Applied Research and Public Policy* 23-25 (1993).

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