VIII- Guidelines

8.1- Need for definition

Insurance contracts laws state that the contract must be written up in utmost good faith otherwise the contract may be void. This means that the applicant is under an obligation to reply honestly, without withholding information. But if the definition of what can be considered genetic information is not clear, how can an applicant reply honestly and how can an insurer ask specific questions which are relevant to risk assessment? Except for the Swiss bill (1998) and the Dutch Act (1998), none of the bills/laws which have been introduced in Europe gives a definition of what constitutes 1) a genetic test, 2) a genetic disease, 3) a genetic predisposition or susceptibility to disease, 4) genetic information and 5) genetic discrimination. There is a need for clear definitions of terms used in genetics, insurance, as well as employment, so that different professions and their clients have a common understanding of the issues. A genetic test is a test of anything that is, or potentially can be, inherited according to mendelian laws. This covers not only DNA, RNA, and chromosome analysis, but also protein truncation test and clinical examination of a patient for a mendelian condition that is diagnosable in that way. But does the test result have predictive value for the subject or family members? If the answer is no, there are no special features. If it is predictive for the subject but not the family, it is ethically similar to several other medical tests. Only if there are also implications for the family is there a special case. It is also important to distinguish between research and clinical genetic tests. A lot of people's worries concern tests for disease susceptibility, and these are almost always part of research, but only clinically validated tests should be considered for insurance purposes. Legislation without a precise definition of these terms may confuse insurers and applicants when underwriting or renewing an insurance policy.

In other respects, differential treatment of persons according to their genetic constitution is not inherently discriminatory; some discriminations are legitimate (Mauron 1997). With insurance, there are two perspectives on genetic discrimination: 1) the actuarial viewpoint: genetic discrimination is unfair only if it is unjustified, i.e. based on faulty risk assessment; actuarial fairness means that everyone should be treated in proportion to the risk it represents for the insured collectivity; 2) the social justice viewpoint: genetic discrimination may be unjust when it is actuarially justified, i.e. based on correct risk assessments, if it involves restriction of social benefits that society has decided should be available equally to all.

Insurers are told that unfavorable genetic tests must be ignored. Ultimately, objections to use of genetic information will be subsumed by economic and scientific realities: individually underwritten insurance cannot be sold without risk classification, and some of the medical information needed to classify risks will be genetic (Pokorski 1997). It will become increasingly difficult to distinguish genetic from nongenetic diseases, genetic information from nongenetic information, or to talk of medical and genetic tests as separate categories.

8.2- Need for more medical, epidemiological and psychosocial research

Some published works indicate that despite the significant scientific progress, there are currently not sufficient grounds for requiring individuals to undergo genetic testing and to

disclose genetic test results to insurers or employers. This is because the current state of knowledge about patterns of genetic test results does not generally support good predictions of the incidence, timing and severity of disease or of time of death (Association of British Insurers 1997, Harper 1997, Human Genetics Advisory Committee 1997). Further research is needed in order to yield useful information. Well-described conditions such as Huntington disease have yielded such information, but this has been gathered over periods of several years. In the United Kingdom, there has been public disquiet following the ABI report and personal experience has shown increased anxiety regarding testing in cancer genetics and Huntington disease clinics (Morrison 1998). Some of the public have found that negative genetic test results can be used to their advantage in lowering already high premiums (Ibid).

8.3- Progress in the legislation in all countries

The laws of nations differ with respect to the issues above and these laws are subject to debate, evolution and change. Today, six European countries have enacted laws to restrict the use of genetic information by insurers and employers. Three European countries have introduced bills or recommendations to prohibit use of genetic information by insurers and employers. These legislative activities at the state level show a growing consensus on the need to define the use of genetic information for insurance and employment purposes. However, a state law is not enough to provide a comprehensive solution to genetic discrimination in insurance and employment. A distinction should be made between using genetic information from medical files and requesting genetic tests, as well as between requesting information from applicants and requesting genetic tests. One cannot be certain in the present economic context, that pressure might not be put upon applicants for an insurance contract or for a job in order to obtain genetic information about them. Nor can one exclude the possibility that the candidates themselves might wish to produce the information spontaneously if it were in their favor. Although it seems difficult to totally eliminate this risk, it could be reduced by a strict limitation of conditions of prescription of tests (French National Consultative Ethics Committee 1995).

The European Data Protection Act (1998) should also have implications in this area, especially about the degree of confidentiality which insurers and employers should apply to genetic test results. This is especially important because most informed-consent forms for data collection state that the information obtained will remain confidential. Without protection, data can reveal not only information on the individual that might be used for identification, but also information that could identify others or that could reveal information on relationships affecting others.

The fear of genetic discrimination by insurers and employers has spread throughout society (Reilly 1998, Williams et al 1999). It is likely that many people who might benefit from such testing will be reluctant to be tested unless laws are in place to protect them. Education is needed. Insurance decisions are sometimes made by inexperienced people, or because of a lack of knowledge about particular genetic conditions. Some basic education and sources for referral are in order. We need to protect people who are already symptomatic as well as people who might be asked to undergo genetic tests.

8.4- Necessity for dialogue and for a greater faith

The dilemma of predictive medicine of having few effective treatments may be resolved in the future. During the next decade, many genetic tests will be performed, primarily on people at high risk of disease. Genetic testing will be readily available in doctors' offices and free-standing commercial laboratories. Insurers are concerned that many individuals could attempt to use genetic test results to create an estate when none would have existed prior to testing and for many people, the temptation to buy insurance under these circumstances could be irresistible (Pokorski 1997). Those opposed to sharing genetic information with insurers argue that antiselection will be a rare event (Zick et al 2000). Although insurance companies may vary in the stringency with which they scrutinize medical record or use research data to determine insurability, one denial may have far-reaching effects on the individual's opportunities from other insurers. Although preventing insurance companies from accessing genetic information may produce adverse selection for insurance, the need for individuals to participate in genetic studies or to undergo genetic testing in order to obtain improved medical management should be considered.

Several avenues exist for preventing genetic discrimination and numerous papers have discussed the need for protecting the confidentiality of genetic data (Earley & Strong 1995). A certificate of confidentiality, like in the United States for the protection of research data could be a valuable tool for protecting genetic data (Earley & Strong 1995). This certificate prevents genetic information from being used for any purpose other than covered in the informed consent. The certificate does not prevent voluntary disclosure of information. Any information about an individual can be released with request or consent of that individual. However, release of information about a family requires the consent of each of the family members. If individuals are minors or incapable, their guardians are able to consent to the release of information. The protection provided is permanent and remains in place even after the death of the individual. This is important because of the lack of independence of genetic and family study data.

8.5- Sub-population in Europe which may be given special treatment

The principle that policyholders in general may have to incur modest extra costs to enable certain minorities to be treated as normally as possible is not novel. The same principle might be applied for those facing genetic risks, such as families at risk from severe and incurable monogenic diseases of late onset, carriers of mutations which have an impact on life expectancy. The advances in human genetics will be important in helping to achieve better health for populations at risk. However, these advances will only be acceptable if their application is carried out ethically, with regard to autonomy, justice, education and the beliefs and laws of each nation and community.

For instance, new genetic technologies open up the possibility of predictive screening, both for individual genetic risk factors for late onset hereditary disease and for susceptibility to workplace hazards. Although the initiative for testing may lie with employers and employees there are many potential stakeholders--from family members and workplace colleagues to insurers and society in general. Consequently, the role of the occupational health professional will not only involve the contextual interpretation of genetic test results but also the myriad of associated ethical questions (Rawbone 1999).

IX- Discussion: Unresolved issues

One of the most complex policy issues accompanying the developments in genetic knowledge relates to how the results of genetic tests are to be used. To discuss the technical, social, and ethical issues of genetic information and testing in insurance and employment, an international workshop was organized by the European Society of Human Genetics Public and Professional Policy Committee in Manchester, The United Kingdom, February, 25-27, 2000. An international group of experts, including representatives of patients organizations was invited.

The formal workshop presentations covered the following themes: the fundamentals of genetics, of insurance, family histories, actuarial relevance and genetic testing and employment issues. Small multi-disciplinary groups were convened to take these discussions further, in particular to consider the specific issues involved in employment, life insurance, private medical insurance, long term care and critical illness insurance, and total permanent disability and income replacement insurance. Their initial task was to explore the insurance needs and rights in the countries represented and to consider the extent to which these needs were currently being met. Following the small group sessions, conclusions were fed back to the whole group where there were opportunities for further discussion.

9.1- Background

The comments and conclusions of the individual working groups were collated under 11 headings: *Definitions, Types and functions of insurance, Insurance for the genetically disadvantaged, Genetic (and other) information sought by insurers, Access to information, Predicative capability of genetic tests, Issues for the insurance industry, Employment, Good practice, Public understanding, Regulatory issues,* and *Research.*

There was considerable agreement on many points, such as the need for clear definitions of the terms used in genetics and insurance, transparency of the process by which genetic information is incorporated into insurance decisions, the importance of confidentiality of genetic information and ensuring that such information is not used to the detriment of other family members. There was broad consensus that insurance considerations should not unduly influence the uptake of appropriate clinical care, which may increasingly involve genetic tests. There was a broad consensus that applicants should not be asked to undergo genetic tests, in order to obtain insurance.

Without in any way belittling the importance of these areas of consensus, or the considerable challenge of implementing and maintaining good practice in these areas, the remainder of this paper attempts to tease out some unresolved issues from the discussions groups, for broader consideration.

The starting position of the insurance industry is to regard genetic information as just part of the (predictive) information that they should be able to use in deciding to accept a private, voluntary application or in setting the premium level. The practice of some clinicians to advise people to buy insurance before having a presymptomatic genetic test highlights the current perception that people at high genetic risk of late-onset disease face the additional social disadvantage of higher premiums or application rejection. It also raises the potential for

adverse selection. But it has been argued that only individuals with mutations for late onset untreatable diseases will be able to deceive the industry. The number of such diseases will probably also be reduce as treatment will be available for these diseases. As the number of individuals that will have the opportunity to deceive the insurance industry is very few and thus the cost for the industry for adverse selection is very low, then why individuals integrity could not be protected now? Only when and if the development of genetic testing can be proven to threat the insurance companies economy, then the economy of the insurance companies and the interest of society could be weighed against the risk for loss of integrity for individuals who had done a presymptomatic test.

The 1997 Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Applications of Biology and Medicine (still to be ratified by many member states) specifies in Article 11: "Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited". In attempting to develop practice fair to both insured and insurer, it was widely accepted that there is a need for clarification of the best means for determining the extent of increased genetic risk of late onset disease, so that there is demonstrable evidence of validity and consistency in the use of any genetic information in underwriting.

Much of the discussion of the workshop addressed two main issues: How to meet the (insurance) needs of those at a genetic disadvantage. The validity and consistency in use of genetic information in insurance.

9.2- Meeting basic needs

The definition of what 'basic needs' are to be covered is a matter for social and political negotiation within each country, but includes healthcare, funds for a basic quality of life (including housing) and an occupation. There is a clear case for a solidarity-based system for basic needs, with optional extras being provided through a system based on mutuality. Insurance with respect to basic needs has often been compulsory (state or private). There is an issue as to how much 'solidarity for basic needs' can be incorporated into private, voluntary insurance without serious threat to the industry (through adverse selection for example). If it is considered that a substantial solidarity element can be provided by the private sector, the questions arise as to who should finance this solidarity and whether guidelines or legislation are required to regulate this insurance.

Basic life insurance: Two countries represented at the workshop, Sweden and the Netherlands, have a ceiling below which no genetic information (genetic test results or family history) has to be disclosed. The Association of British Insurers' Voluntary Code of Practice has a ceiling for a life insurance related to house purchase below which genetic test results do not have to be disclosed, but relevant family history still does. Finland has a more general prohibition on using genetic test results and/or family history in insurance, whilst in Austria the prohibition extends only to genetic test results and not family history.

Genetic and insurance professionals need to resolve the issue of whether genetic test results and family history should always be lumped together as 'genetic information'. A valid explanation for selecting a particular ceiling also needs to be provided and should relate to the point where basic economic security (basic house purchase, necessary provision for dependants and protection for the self employed) gives way to personal investment.

Basic health and social insurance: In European societies there is a general consensus that society should provide basic medical care for all members of society, and basic personal care for those unable to care for themselves. The economic pressure on governments to increase the contribution of private, voluntary insurance to long term care presents a challenge to discover what can be provided by the industry in the absence of genetic information. More research is needed.

The key challenge is to protect the basic needs of the few people with a significant family history or risk of late onset monogenic disease, because they are most at risk of falling between the benefits provided for those whose health is already affected, and insurance provisions offered to the healthy public.

9.3- Predictive genetic information in insurance

Most of the discussion concerns the use of predictive DNA test results in insurance evaluation. There is however a practical issue surrounding the boundary between predictive 'genetic information' and other health-relevant data. A person's sex is genetic information predictive of health outcomes, but being overt and covered by its own anti-discrimination legislation would not normally be included within 'genetic information' for insurance purposes. There has not been adequate discussion or agreement, on what other (non DNA test) indicators of genetic disease might be used validly by insurers as part of their underwriting assessment process.

Most important was the issue of family history. There was broad acceptance that the family history was predictive 'genetic information', although it was recognized that the self-reported family history may be inaccurate. There is a need to resolve inconsistencies in current attitudes and policies on use of family history in relation to the use of genetic test results. If the ceiling for life insurance cover, without use of 'genetic information' is intended to allow all healthy people to obtain this basic cover without disclosure of their genetic risk of late onset disease, then it is illogical to still take family history into account. Most of the high risks relevant to life insurance that are contained in genetic test results are revealed by an accurate family history. Thus it would be of little benefit to the genetically disadvantaged if a company agreed to forego the use of genetic test results, but would still require family history information. It may also generates social pressure on a would-be applicant to have a genetic test and disclose a negative result to show that their family history does not put them at increase risk.

Valid use of genetic information: It was agreed that any use of genetic information to predict risk of disease or death in insurance must be able to withstand independent scientific scrutiny. There was large support for the view that consumer and commercial confidence in the validity of the use of genetic information in underwriting in particular situations is best maintained by an independent review system. However, it had been argued that in insurance medicine, genetic tests are never considered as a stand alone criteria but rather embedded in an overall medical context. Underwriting is a multifactorial and complex process which can not be broken down in to single step decisions.

The predictive power of genetic variants for common late-onset diseases: Because of the uncertainty that surrounds the predictive power of specified genetic polymorphisms as

contributors to health-threatening behavior, susceptibility to noxious substances in the environment or maladaptive metabolic response to our current diet most of the insurance industry maintains a cautious stance. This was illustrated by the comment '*Multifactorial risks – don't be too quick to discount their relevance in underwriting. There is much variation in life expectancy. How much is genetically determined? What proportion of that genetic risk will be elucidated in due course?'*

This cautionary note was in response to a fairly wide consensus by geneticists illustrated by the comment *'The limited number of classic Mendelian dominant conditions with a high predictive certainty resulting from their presence means that genetic testing is probably a much smaller issue than is often supposed. It seems most people will turn out to have modestly increased risks for something - which are already taken account of in the pooling or will be too small to be worth insurers incurring the transaction costs of collection and analysis'*. It is difficult to predict the extent to which genetic tests might become relevant for health prediction in complex diseases, and even more difficult to predict the extent of their influence and timing of such advances in knowledge. A genetic predisposition test cannot be regarded as a diagnostic test but rather as a prognostic factor because, at the time the genetic test is performed, there is not yet a disease established. In so fare there is no gold standard, which can be set in reference to this test. However one can compare how many tested persons have a positive result and how many a negative result and how many will develop a certain disease during a period. The final result is a likelihood of disease and not a predictive value which can then be expressed as a relative risk. Therefore, it was agreed, as with all genetic information used in an insurance context, that sound knowledge of the real predictive value of the information needs to be accrued and validated before being put into practice. It is also important that customers should be clearly aware, of the limits of genetic information that is required and utilized by the insurance industry, in relation to these complex disorders.

9.4- Genetic information and Employment

In contrast with insurance practices, the possible consequences of genetic tests on employment practices received less attention. It was noted that there is currently very little use of genetic information in relation to employment. There was a broad consensus that it is usually not acceptable for people to be excluded from particular types or areas of employment or advancement because of genetic test results or family history, which are not relevant to assessing an individual's *current* ability to do a specific job. The exceptions would be to protect the employee from a specific hazard. If there are genetic markers for sensitivity to some occupational hazard, exposed workers will have a real interest in seeing that the information is used to protect their health, and provided that this information is used responsibly and fairly for both sides (Galton & Ferns 1999).

A new model for employment was proposed in which employment related tests or monitoring is provided by and supervised by an independent agency, not the employer. The tests would be voluntary, except to protect specific hazards (e.g. radiation, dust, chemicals) to be specified by the agency, not the employer. The voluntary test results would be available only to the employee. The mandatory test results would be available to people specified by the agency.

Conclusion

There are diverging approaches among the various states which have sought to establish binding norms. Can a law provide a solution to the problems of insurance, employment and genetics? In practice, a law provides little security: how can an individual prove that (s)he was discriminated against because of a genetic disease? Otherwise, must genetic information be protected and how? Firstly, there is little consensus on the definitions of what should be considered genetic information and what should not. Secondly, the type of genetic information available today appears hardly relevant to the insurers and employers, except in the case of a few rare monogenic disorders. For most common diseases, genetic information is too subject to variations and irrelevant for insurers and employers. This is why the British government has decided that only an independent Commission may decide which tests are relevant to insurance companies. It is accepted that in time when more reliable actuarial data are available for single gene disorders, genetic test results may be used but it is felt strongly that for multifactorial diseases the results should not be used. Most susceptibility genes are already shared by many people currently insured at standard rates. The unfolding of such results would stratify society in an unacceptable way.

It seems that fears that the results of genetic tests could be misused by insurers and employers are exaggerated and yet the fear of genetic discrimination remains intense; perhaps because there are very little data to support or refute that discrimination is actually taking place. In the same time, there appears to be a lack of knowledge about genetics in the insurance industry. Consequently, how to reassure people and protect them? Should insurers only require information about previous genetic test results for policies above a certain value? Or should we continue with moratoria? In some countries, insurance companies have chosen to impose an industry-wide moratorium, until genetic information becomes less uncertain. It is at this point that the real issues will come to light. Among other solutions, if Codes of practices can be applied without legislation, could there be adequate protection for all parties, in ways which are flexible? When compared to laws, Codes of practice may be more amenable to development and evolution as genetic knowledge increases.

REFERENCES

The Ad Hoc Committee on Genetic Testing/Insurance Issues, BACKGROUND STATEMENT Genetic Testing and Insurance, American Journal of Human Genetics, 56, 1995:327-31.

Berg P. & M.F. Singer, Genetic testing and insurance, Nature, 380, 1996:385-6.

Bodmer W., Genetic testing and insurance, Nature, 380, 1996:384-5.

Bonn D., Genetic testing and insurance: fears unfounded? The Lancet, 355, 2000:1526.

British Society for Human Genetics, Statement on Genetics and Life Insurance, May 1998.

Chuffart A., Genetics and Life Insurance: A Few Thoughts, Swiss Re Zurich, 1997.

Cook ED, Genetics and the British insurance industry, J Med Ethics, 25, 2, 1999:157-62.

Cunningham GC, The genetics revolution, Postgraduate Medicine, 108, 1, 2000:193-202.

Department of Health & Human Services - USA, Report of the Secretary to the President Health Insurance in the Age of Genetics, July 1997.

Earley CL, Strong LC, Certificates of confidentiality: a valuable tool for protecting genetic data, Am J Hum Genet, 57, 3, 1995:727-31.

EUROSCREEN Insurance Sub-Group, Insurance, Newsletter 7, Spring 1997.

Ewald F. & J.H. Lorenzi (eds), Encyclopédie de l'assurance, Economica, 1997

Feingold J, Misuse of genetic tests by insurance companies, Rev Epidemiol Sante Publique, 47, 2, 1999:190-1.

Galton DJ, Ferns GA, Genetic markers to predict polygenic disease: a new problem for social genetics, QJM, 92, 4, 1999:223-32.

Geller G., Tambor E.S., Bernhardt B.A., Chase G.A., Hofman K.J., Faden R.R., Holtzman N.A., Physicians' Attitudes toward Disclosure of Genetic Information to Third Parties, The Journal of Law, Medicine & Ethics, 21(1), 1993:238-40.

Glazier A.K., Genetic predispositions, prophylactic treatments and private health insurance: nothing is better than a good pair of genes, American journal of Law and Medicine, 23(1), 1997:45-68.

Goedvolk V.I., The Medical Examinations Act: practical experience from the Netherlands, International Conference on Genetics and Private Life/Health Insurance, Paris, 11-12 February 1999.

Hall M., Rich S., Laws Restricting Health Insurers' Use of Genetic Information: Impact on Genetic Discrimination, am. J. Hum. Genet, 66, 2000:293-307.

Harper P.S., Genetic testing, life insurance, and adverse selection, Philosophical Transactions of the Royal Society of London 352 (1357), 1997:1063-6.

Hauser G. & A. Jenisch, Laws regarding insurance companies, Journal of Medical Genetics, 35, 1998:526-8.

Holtzman N.A., Are we ready to screen for inherited susceptibility to cancer? Oncology, 10, 1996:57-64.

Human Genetics Advisory Committee, The implications of genetic testing for insurance, London 1997.

Jacobs L.A., At-Risk for Cancer: Genetic Discrimination in the Workplace, Oncology Nursing Forum, 25(3), 1998:475-80.

Jaeger A.S. & W.F. Mulholland II, Impact of Genetic Privacy Legislation on Insurer Behavior, Genetic Testing, 4, 1, 2000:31-42.

Jecker N.S., Genetic Testing and Social Responsibility of Private Health Insurance Companies, The Journal of Law, Medicine & Ethics, 21(1), 1993:109-16.

Karlic H. & A. Horak, Proceedings Genetic Testing in Europe: Harmonisation of Standards and Regulations, Vienna: Symposium 30.10.1998.

Kevles D.J. & L. Hood, The Code of Codes: Scientific and Social Issues in the Human Genome Project, Cambridge: Harvard University Press, 1992.

Kmietowicz Z., Health put at risk by insurers' demands for gene test results, British Medical Journal, 314, 1997:625.

Kumar S., Gantley M., Tensions between policy makers and general practitioners in implementing new genetics: grounded theory interview study, BMJ, 319, 7222, 1999:1410-3.

Lapham E.V., Kozma C., Weiss J.O., Genetic Discrimination: Perspectives of Consumers, Science, 274, 1996:621-4.

Lauth A & J Schmidtke, Gedankenaustausch zum thema Lebensversicherung und Genetik, Medizinische Genetik, 1999.

Le Grys D.J., Actuarial considerations on genetic testing, Philosophical Transactions of the Royal Society of London 352 (1357), 1997:1057-61.

Lemmens T. & P. Bahamin, Genetics in Life, Disability and Additional Health Insurance in Canada: A Comparative Legal and Ethical Analysis, in Knoppers B.M. (Ed) Socio-Ethical Issues in Human Genetics, Les Editions Yvon Blais Inc., 1998:107-276.

Lowden J.A., Certificates of Confidentiality, American Journal of Human Genetics, 58(1), 1996:436-7.

MacDonald A.S., How will improved forecasts of individual lifetimes affect underwriting? Philosophical Transactions of the Royal Society of London 352 (1357), 1997:1067-75.

Martin G.J., Tests génétiques et assurances, CREDECO, CNRS.

Mauron A., Médecine prédictive et destinées individuelles: la tension entre équité actuarielle et justice sociale, Journal of International Bioethics, 7, 1997:304-10.

McEwen J.E. et al., A survey of medical directors of life insurance companies concerning use of genetic information, American Journal of Human Genetics, 53(1), 1993:33-45.

McGleenan T., Wiesing U. and Ewald F. (eds) Genetics and Insurance. BIOS Scientific Publishers Ltd, Oxford, 1999.

McNeilly R.H., Genetics & Insurance - The Situation in England, International Conference on Genetics and Private Life/Health Insurance, Paris, 11-12 February 1999.

Miller J., Physician-Patient Confidentiality and Familial Access to Genetic Information, Health L. J., 2(141), 1994:151.

Morrison P.J., Genetic testing and insurance in the United Kingdom, Clinical Genetics, 54, 1998:375-9.

Morrison P.J., Steel C.M., Vasen H.F., Eccles D., Evans D.G., Moller P., Hodgson S., Stoppa-Lyonnet D., Chang-Claude J., Caligo M., Olah E., Haites N.E., Nevin N.C., Insurance implications for individuals with a high risk of breast and ovarian cancer in Europe, Dis Markers, 15, 1-3, 1999:159-65.

National Consultative Ethics Committee, Opinion and Recommendations on Genetics and Medicine: from Prediction to Prevention, Report 46, Paris, 1995.

Natowicz M.R., Alper J.K. & J.S. Alper, Genetic discrimination and the law, American Journal of Human Genetics, 50, 1992:465-75.

Niermeijer MF, Cancer Genetics and Insurance, American Journal of Human Genetics, 64(1), 1999:328-9.

Noonan R. & P. Roth, Genetic Testing and Insurance Discrimination: Challenges for Nurses in Advanced Practice, Advanced Practice Nursing Quarterly, 3(3), 1997:20-30.

Nys H. & al., Predictive Genetic Information and Life Insurance: Legal Aspects: Towards European Policy? University of Limburg, Department of Health Law, Maastricht, 1993.

Park N. & B. Dickens, Legal and Ethical Issues in Genetic Prediction and Genetic Counseling for Breast, Ovarian and Colon Cancer Susceptibility, in Taylor K.M. & D. De Petrillo (Eds), Critical Choices: Ethical, Legal and Sociobehavioural Implications of Heritable Breast,

Ovarian and Colon Cancer: Background Paper for the International Research and Policy Symposium, Toronto, 1995.

Pokorski R.J., Insurance underwriting in the genetic era, American Journal of Human Genetics, 60(1), 1997:205-16.

Rawbone RG, Future impact of genetic screening in occupational and environmental medicine, Occup Environ Med, 56, 11, 1999:721-4.

Reilly P.R., Genetic Risk Assessment and Insurance, Genetic Testing, 2, 1998:1-2.

Roscam-Abbing H.D.C., Predictive Genetic Knowledge, Insurance and the Legal Position of the Individual, in Swiss Institute of Comparative Law (Ed), Human genetic analysis and the protection of personality and privacy, International coloquium, Lausanne: Swiss Institute of Comparative Law, 1994.

Rosén E., Genetic information and genetic discrimination how medical records vitiate legal protection, Scand. J. Public Health, 27, 1999:166-72.

Ross T., The likely financial effects on individuals, industry and commerce of the use of genetic information, Philosophical Transactions of the Royal Society of London 352 (1357), 1997:1103-6.

Rothenberg K., Fuller B., Rothstein M., Duster T., Kahn M.J.E., Cunningham R., Fine B., Hudson K., King M.C., Murphy P., Swergold G., Collins F., Genetic Information and the Workplace: Legislative Approaches and Policy Challenges, Science, 275(21), 1997:1755-7.

Rothstein M.A., Genetic Testing: Employability, Insurability, and Health Reform, Journal of the National Cancer Institute Monographs No. 17, 1995:87-90.

Sandberg P., Genetic information and life insurance: a proposal for an ethical European policy, Social Science and Medicine, 40(11), 1995:1549-59.

Scanlon C., The legal implications of genetic testing, RN, 61(3), 1998:61-5.

The Nuffield Trust Genetics Scenario Project, Genetics and Health. Policy issues for genetic science and their implications for health and health services, The Stationnery Office, 2000.

Watts G, Fears that a rise in genetic testing will rule out insurance are "paranoia", BMJ, 319, 7205, 1999:273.

Wichman A., Smith J., Mills D., Sandler A.L., Collaborative Research Involving Human Subjects: A Survey of Researchers Using International Single Project Assurances, IRB A publication of The Hastings Center, 19(1), 1997:1-6.

Wilkie T., Genetics and insurance in Britain: why more than just the Atlantic divides the English-speaking nations, Nature Genetics, 20, 1998:119-21.

Williams JK, Schutte DL, Evers CA, Forcucci C, Adults seeking presymptomatic gene testing for Huntington disease, Image J Nurs Sch, 31, 2, 1999:109-14.

Wingrove K.J., Norris J., Barton P.L., Hagerman R., Experiences and Attitudes Concerning Genetic Testing and Insurance in a Colorado Population: A Survey of Families Diagnosed With Fragile X Syndrome, American Journal of Medical Genetics, 64, 1996:378-81.

Zick CD, Smith KR, Mayer RN, Botkin JR, Genetic testing, adverse selection, and the demand for life insurance, Am J Med Genet, 93, 1, 2000:29-39.

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This document was discussed during a workshop in Manchester (UK), February, 25-27, 2000 where 47 experts from 14 European countries were invited. The workshop was organized by Martin Bobrow, Peter Farndon, Marcus Pembrey, and Sandy Raeburn.

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This document formes part of a BIOTECH programme financed by the Commission of the European Communities (CEE BIO4–CT98–0550).

(19 January 2001)