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Genetic Testing and Insurance: International Regulation

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GENETIC TESTING AND INSURANCE

INTERNATIONAL REGULATION

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“GENE TESTS FOR LIFE COVER”

“GENETIC TESTING COULD CREATE A NEW UNDERCLASS”

“BEWARE : GENES COULD COST YOU YOUR JOB”

“THE BRAVE NEW WORLD IS A MORAL MINEFIELD”

“GENETIC DISORDERS RULE OUT LIFE INSURANCE COVER”

“INSURERS CONDEMN GENETIC TEST SECRECY”

These are headlines which have appeared in Australian newspapers over the last three years. If people believe what they read in the newspapers, it is likely that many will be concerned about the impact of the genetic revolution - and in particular, they will be concerned about the use of genetic testing in insurance.

People are likely to be most concerned about those individuals who have serious genetic defects. Will they be subject to discriminatory treatment from insurers ? Will they be unable to obtain insurance ? Is this fair ? At present, theoretically, all are vulnerable. No one knows what the next genetic test may reveal - so everyone is at risk of falling into the “genetic underclass”.

On the other hand, some people are more concerned with the welfare of insurance companies. Suppose that people with genetic defects are permitted to purchase large insurance policies. Will insurers face financial ruin ? One American actuary has commented that:

“If you thought that AIDS was bad for the industry, genetics is much worse. Bad legislation has the opportunity to devastate the industry.”(37)

The following paper examines the developments in the regulation of genetic testing around the world.

Section 1 provides some background information about developments in genetic testing, and current practice in underwriting.

Section 2 presents three different regulatory approaches, along with the arguments for and against each approach.

Section 3 summarises the developments in the regulation of genetic testing in the United States, the UK, the European Community, Canada, New Zealand, and Australia. There is considerable variety in the approaches adopted in different countries: some countries have introduced a complete ban on the use of genetic information in underwriting; others have allowed insurers a free rein, imposing no restrictions at all.

It should be noted that this paper will almost certainly be out of date by the time it is completed. As we write, new legislation is under consideration in several jurisdictions. Various actuarial bodies and universities are holding conferences, designed to find new solutions to the problems identified below. To help keep readers up-to-date, this paper identifies some sources of information which are useful in monitoring new developments.

SECTION 1 : BACKGROUND

1.1 The Human Genome Project

The Human Genome Project, established in 1987, is funded by the US Department of Energy and the National Institutes of Health. The aim of the project is to map out the entire genetic makeup of the human body, which includes 50,000 to 100,000 genes. The researchers have already made significant progress : in the first five years of the project, more than fifty new tests for genetic conditions were developed (24). People can now be tested for genetic diseases such as Huntington's chorea, cystic fibrosis, and muscular dystrophy. The researchers have identified genes which are linked to higher risks of breast cancer, colon cancer, heart disease, and Alzheimer's disease. (23)

At present, only about 6,000 genes have been identified, but new discoveries are announced almost daily (23). It is likely that the entire human genome will be mapped by the year 2015. (22)

What are the implications of this new technology for insurers ?

1.2 CURRENT PRACTICES IN INSURANCE

At present it appears that few, if any, insurers require applicants for insurance to undergo genetic tests. However, most insurers will ask applicants to disclose the results of previous genetic tests which have been taken for medical reasons (6,7, 52).

Why don't insurers require genetic testing as a condition of insurance ?

Firstly, it is too expensive. An American actuary commented that :

“Today, genetic tests are still much too expensive to become part of routine insurance underwriting. Typically, an insurer can afford to spend only \$25 to \$30 on all the tests associated with the underwriting process, and most of this allowable expense is already spoken for in testing for tobacco and alcohol use, cholesterol levels, and other information far more critical to insurers than genetic information. At least partly because of the expense, insurers are not currently requiring DNA-based tests for life insurance ”(6)

Secondly, at present many of the existing genetic tests do not provide information which is very useful to insurers.

Many of the existing tests are tests for monogenic conditions, where a defect in a specific gene causes a specific disease. These tests have a high predictive value, but they have limited utility in underwriting life insurance. For most serious monogenic diseases, symptoms commonly appear at an early age, and few survive to the age where life insurance is required. A few monogenic diseases, such as Huntington's chorea, have a late onset (symptoms appear at about

age 40). But these are relatively rare, and there is usually a family history of the disease which enables insurers to identify those at risk. (38)

There are also some tests for multifactorial genetic defects, which indicate a predisposition to disease when combined with certain environmental factors. Again, at present, these are not very useful to insurers. As Lockyer points out (4):

“It remains a fact that we know little of the all-important interaction between multifactorial genetic defects and other behavioural and environmental factors. The equivocal value of the knowledge that might be gained means that, as yet, genetic testing has little value as a tool of the insurance underwriter. Other tests for predisposition to many of the common disorders are more readily available - blood tests, urinalyses, blood pressure readings, etc.”

Another actuary has pointed out that it will take a long time to collect and analyse the data from the new tests. He suggests that “there is no imminent likelihood of any serious rating being carried out by the insurance industry in relation to genetic characteristics, because the information simply will not be available in a sufficiently reliable form for them to use.” (28)

Is it likely that insurers will require genetic testing in the future ?

American, British, and European insurers have stated that they do not expect any significant changes to existing practice, in the near future - say, the next five to ten years (4, 7, 35, 52). However, in the longer term, circumstances may lead insurers to review their approach.

Firstly, the cost of genetic tests is likely to fall; at the same time, the accuracy of predictions should improve. The medical use of genetic tests is likely to increase. This would make it more feasible for insurers to use genetic information.

Secondly, the insurance market is competitive. As Lockyer points out (4), if one insurer starts using genetic tests to screen life insurance applicants, then this company might be able to offer lower premium rates and attract a high proportion of the better risks, i.e. “cherry picking”. Other insurers would be forced to follow suit.

Hence, in the absence of any regulation, it is likely that insurers will eventually decide to use genetic tests as a routine part of underwriting, like any other medical test.

2. OPTIONS FOR REGULATION

There are three basic alternatives for regulation.

1. No restrictions on insurers
2. Require disclosure of the results of previous test, without further testing by insurers
3. A ban on the use of any genetic information

Before we look at the legislative options, it would be desirable to clarify what we mean by the term “genetic tests”. Unfortunately, this is a difficult task. Genetic testing means different things to different people.

Most insurers suggest that we adopt a narrow definition of genetic tests, for example:

“Genetic tests are laboratory tests of human DNA or chromosomes, used to identify the presence or absence of inherited or congenital alterations in genetic material that are associated with disease or illness.”

However, in many cases, genetic defects are identified by examining “gene products”, e.g. the proteins which are produced by these genes. Hence some suggest that the definition of genetic testing should include any test of gene products.

If we broaden the definition to include gene products, then we will be including some tests which are already routinely performed as part of the underwriting process. For example, a genetic defect causes familial hypercholesterolemia - many insurance companies already use cholesterol tests to screen applicants. Should cholesterol tests be included in the definition of genetic testing ?

The scientific details are beyond the scope of this paper - suffice it to say that medical experts agree that “there is no clear boundary between genetic and nongenetic conditions or tests” (33). Hence, “for policy purposes, it will be increasingly difficult to distinguish genetic diseases from non-genetic diseases, and genetic information from non-genetic information” (24).

At the extreme, we could adopt a very broad definition. At present, underwriters try to assess the possibility of a genetic defect by inquiring about family history. If it is unfair to use DNA tests to identify genetic defects, is it also unfair to ban the use of family histories ? Such restrictions have already been proposed in some states in the United States, in relation to health insurance.

In summary, the definition of genetic tests in legislation is a problem. If it is too vague, it will lead to endless disputes; if it is too narrow, it will be ineffective; if it is too broad, it will put the overturn accepted underwriting practices. (52)

2.1. No Restrictions

Many insurers advocate freedom from any legislative restrictions: that is, insurers should be allowed to ask for the results of previous tests, and/or ask applicants to take genetic tests as a prerequisite for cover. After considering the available evidence, insurers should be allowed to charge extra premiums, impose exclusions, or deny coverage.

Insurers argue that the use of genetic information is simply part of “the right to underwrite”. Underwriting is necessary in order to classify risks fairly and charge appropriate premiums. If insurers are not allowed to underwrite, then the insurers will be exposed to adverse selection, which would lead to higher premium rates and/or endanger solvency. Insurers argue that genetic information should not be treated any differently to other medical information.

In opposition, the following arguments have been presented:

- It will lead to an increase in the number of people who are uninsurable
- Insurance should spread risks across the community
- People have “the right not to know” about genetic defects
- Insurers cannot be trusted to use genetic information fairly
- Genetic information is too private to share with insurers

An increase in the number of people who are uninsurable

If insurers are allowed to use genetic data, some people will not be able to obtain any insurance, or may be charged very high premiums. Genetic tests may lead to an increase in the number of people who are effectively uninsurable.

Some argue that insurance is a necessity, and society has an obligation to ensure that insurance is available to all. This argument is particularly common in the USA, in relation to health insurance. In the USA, for most people, if you don't have health insurance, you don't get medical care. The availability of insurance can be, literally, a matter of life and death. For example, there is now a genetic test which indicates susceptibility to breast cancer - what are the consequences if an insurer refuses cover on the basis of such a test? One woman explained the consequences :

“You cannot survive breast cancer without health insurance. You simply die from it. You may find a doctor who will do a mastectomy. You may find a hospital who will give you a chance to pay on this bill. You can't get chemotherapy. You can't get radiation therapy. The risk that they may not be able to be insured will change my children's lives forever.”(15)

Clearly, in the USA, under the current health care system, the use of genetic testing by insurers may lead to tragic consequences for many people. In most other countries, health care is available without private insurance, so genetic testing for health insurance is not an issue. The debate centers on the availability of life insurance.

Some argue that life insurance is also a necessity - or at least, it is socially desirable to maintain wide availability of insurance. As we shall see, some government committees have adopted this viewpoint. And there is some support for this view in the general public: a survey of Americans found that 54% agreed with the statement that “Life Insurance companies should be required to sell a basic level of life insurance to all applicants, regardless of their health and the risk they represent”. (5)

In some cases, the availability of life insurance affects the availability of other services. For example, in the UK, life insurance is often required as a condition for obtaining a home mortgage loan. This strengthens the argument that life insurance should be widely available. Hence, in the UK, there are proposals to forbid the use of genetic information for insurance related to mortgages.

If insurance is a necessity, does this imply “right to insurance” ? Chuffart (52) suggests that:

“Private insurance has now become a predominant element in everyday life (e.g. access to private health care, obtaining a mortgage, paying inheritance tax, etc). Hence in many cases denial of coverage may mean exclusion, which from a social

and political viewpoint is not acceptable....Under these circumstances, it should not come as a surprise that private insurance is increasingly perceived as a right, or to use a fashionable expression, an entitlement.”

If insurance is an entitlement, should insurers be required to provide cover for everyone ? In this context, it is interesting to note recent developments in New Zealand: the Human Rights Act now forbids life insurers from declining any risks (16). In the Netherlands, the government has encouraged the industry to find a way to provide cover for those with a family history of Huntington’s disease. In France, insurers were requested to provide some type of cover to HIV+ people applying for mortgages (52).

Not everyone agrees with this viewpoint.

Firstly, it is not necessarily true that the use of genetic tests will lead to a large increase in the number of people who are uninsurable. Relatively few people will have serious genetic defects. In many cases, genetic testing will show a predisposition to certain diseases - but in many cases this will simply lead to a higher premium, say 10% to 20% above the rates for a standard life. In some cases, people who were previously uninsurable will be able to obtain cover, if they have clear test results. For example, a person with a family history of Huntington’s disease might be uninsurable, with a 50/50 chance of inheriting the disease. After a test, with luck, this person might be acceptable at standard rates.

Indeed, in the long run, new treatments based on genetic technology should lead to improved life expectancy for many people with genetic defects. In the long run, there is likely to be a reduction in the number of people who are unable to obtain insurance (32).

Secondly, even if there is an increase in the number of uninsurables, some argue that there is no imperative to provide insurance for everyone. Insurance agents usually argue (quite persuasively) that nearly everyone needs insurance. But one British actuary pointed out that:

“Life insurance is not seriously a necessity of life. It is an important add-on to the economic systems, but it is not essential for people to have it. You can get loans without life insurance. Most people have group life insurance associated with their employment, and therefore it is not a great problem if people are not able to get life insurance.” (28)

At present, a small percentage of applicants for life insurance are declined, even without genetic testing. If it is acceptable to deny coverage on the basis of existing medical tests, why is it unacceptable to deny coverage on the basis of genetic tests ? It would be inconsistent to allow some high-risk individuals to be insured, while rejecting others.

Solidarity (The socialization of risk)

Some argue that “the social purpose of insurance is to spread risks across communities”. Those who are fortunate enough to have a low risk of death should assist those who, through no fault of their own, have a higher risk of death. How can it be considered fair to charge higher premiums to people “because of a misspelling in a genetic script that they cannot control and did not choose ?” (18)

“We don’t pick our genes ; they should not be used against us”, says the director of the National Human Genome Research Institute (17).

“We find it unacceptable that people afflicted from birth with a genetic predisposition should be faced with additional social obstacles, and that their relatives should also be at a disadvantage in this way” says the Health Council of the Netherlands. (27)

These comments all have the same theme - it is unfair to use risk classifications which depend on factors which are beyond the control of the individual. It might be fair to charge higher premiums to smokers, or to people who voluntarily jump out of airplanes - but it’s not fair to discriminate against those who have genetic defects which are no fault of their own. Surveys of American consumers indicate a considerable degree of support for this view. (5)

In opposing this view, insurers point out there are many other risk classification factors which are beyond the control of the individual, which are currently considered acceptable for underwriting purposes: age and sex are examples. Furthermore, it might be difficult to determine which factors are within the control of the individual, and which are the result of genetic defects. For example, is there an inherited tendency to obesity, or it is the fault of the individual for failing to exercise ? Is there a genetic predisposition to alcoholism ? (13)

Insurers argue that the private voluntary insurance system is not designed to provide cross-subsidies from low-risk to high-risk individuals. If our society wants to provide financial assistance to those who suffer illnesses, then it should do so in a more direct and effective way - for example, by direct payments out of general tax revenue.

The “right not to know”

Some argue that insurers should not be able to require genetic tests as a condition for insurance, because people have a “right not to know”. Suppose that your family history indicates that you are in a high risk group: so there is a significant probability that you have inherited a defective gene which will lead to early death. Suppose that there is no known treatment for the disease. Would you want to take a genetic test ?

Many people say no. Apparently many people at risk from Huntington’s disease do not want to know whether they have the gene, especially because there is no cure (30). Similar attitudes were reported in individuals with a high risk of an inherited tendency for cancer. (20)

The Council for Responsible Genetics argues that :

“If insurance applicants are required to undergo genetic testing as a condition of obtaining insurance, consumers may be obliged to obtain unwarranted information about their genetic inheritance. This burden of knowledge may in turn create feelings of hopelessness and may lead to serious psychological traumas. In many cases, the identification of a gene associated with a particular disease is of no therapeutic value to the consumer. There is a general consensus in the medical

community that coercive medical interventions represent a gross violation of medical ethics.” (78)

This is an argument against compulsory testing - it is not an argument against disclosure of previous test results.

Unfair discrimination

Some doctors are concerned about the misuse of genetic information by insurers. They point out that it would be difficult (and expensive) for insurers to keep up to date with all the latest developments in genetic technology, and results could be easily mis-interpreted. When the tests are so new, the data is often equivocal, and the significance uncertain. One medical geneticist said :

“These tests require expertise to interpret. It makes me nervous that [insurers] are trying to set premiums on the basis of things neither they nor we understand.” (19)

In the case of multi-factorial diseases, it is likely to be quite difficult to assess the extent of extra mortality risk associated with a positive test result. Suppose we know that a person with a certain genetic defect is more likely to suffer from heart disease - but suppose that the extra risk can be reduced by appropriate diet, exercise, and medication. People with a positive test result are more likely to change their lifestyle, have earlier medical intervention, and ultimately be cured (23). The diagnosis will surely improve the prognosis. Hence a positive test result may not necessarily lead to higher mortality. To assess this, underwriters will need to have a great deal of knowledge about the effectiveness of treatment of various genetic defects.

Although insurers might hope that genetic data would never be misused, there is evidence shows that it does sometimes occur. Opponents of genetic testing often cite the American experience with sickle-cell disease. In the 1970s, some American insurers denied coverage to those who tested positive for sickle-cell anaemia. But sickle-cell anaemia is a recessive gene, and many of these people were merely carriers of the disease who would never suffer any symptoms themselves. (14)

Opponents of genetic testing in insurance have documented numerous examples of unjustified discrimination in the USA, in Canada, and in the UK. Billings et al. (10) quotes examples of people who have been denied insurance, even though they are simply carriers of a recessive trait, who will never experience any symptoms. Others have been denied insurance because they have a genetic defect, even though the disease can be controlled by appropriate medication when it is diagnosed at an early stage.

Although evidence of misuse has been presented, it is largely anecdotal and it is difficult to determine the extent of such incidents. Insurers claims that in general, underwriters have dealt responsibly with medical information.

Presumably this problem could be rectified by legislation which would require insurers to justify their underwriting decisions - that is, it would be possible to forbid “unfair” discrimination, while still allowing discrimination which is justified by reasonable actuarial or medical data. This is the approach adopted in Australia, under the Disability

Discrimination Act. People who believe that they have been unfairly treated by insurers can complain to the Human Rights and Equal Opportunity Commission (HREOC).

To date, the HREOC has received about 50 complaints of unfair discrimination by insurers against disabled people. If the complaint is referred to the Commission for a hearing, the matter is usually settled on a confidential basis prior to the hearing. The settlement usually results in the provision of cover. The Disability Discrimination Commissioner has suggested that the insurance industry will need to do more work, collecting more data, to ensure that any discrimination is fair and justifiable. (93)

Privacy Issues

In several countries, there are also major concerns about the confidentiality of data held by insurers. Genetic information is considered to be intensely personal, and there is concern that those with genetic defects may be stigmatised. Can we trust insurers to maintain confidentiality, without inadvertently releasing information to employers or others ?

In the United States, many of the laws relating to genetic testing include strong privacy provisions. The issue of confidentiality has also been raised in Canada, in a report by the Privacy Commissioner. (86)

In Australia, the Privacy Commissioner noted that insurers have generally been responsible in their use of personal information - the Life Insurance Complaints Board has received very few complaints. However, the Commissioner suggested that the industry should adopt a code of practice to protect the confidentiality of genetic data - the rules which are currently applied to HIV/AIDS information could be used as a model. (88)

2.2. The Disclosure Approach

At present, most insurers will ask the applicant to disclose the results of any genetic tests which have been conducted in the past, but they will not require genetic tests. At first glance, this approach appears to solve some of the above problems. But there are some drawbacks.

From the insurer's viewpoint, theoretically, this approach should be satisfactory. The insurer and the applicant both have access to the same information, and hence there is no possibility of adverse selection.

However, this assumes that the applicant is honestly disclosing the results of prior tests. Past experience indicates that this may be overly optimistic. For example, insurers give discounts to non-smokers; saliva tests used to detect cotinine are positive in 5% to 30% of applicants who claim to be non-smokers (7).

At present, it would be difficult for applicants to lie about their genetic tests, since the information is available in medical records. However it is likely that anonymous over-the-counter testing, mail-order testing, and home test kits will be available within the foreseeable future (13). Such tests have already appeared :

“In Britain, mail-order genetic tests became available for the first time last year when the fledgling company University Diagnostics started advertising in Cosmopolitan.

Adults send in 65 pounds and a saliva sample to learn whether they carry the cystic fibrosis gene.”(34)

When testing is anonymous, those with positive test results may be tempted to “forget” to disclose these results when they subsequently apply for insurance. Hence, insurers will want the right to ask for their own tests, to protect against non-disclosure.

From the applicant’s point of view, the disclosure-only approach has some advantages. It eliminates the “the burden of knowledge” problem - people who do not want tests will not be required to take tests. Furthermore, it is likely that fewer people will be declined - those who want insurance can take out insurance, prior to any voluntary genetic testing.

However, once again there are some serious drawbacks.

- Most significantly, some people might refrain from taking tests, because they are afraid that adverse results may lead to difficulties in obtaining insurance. Several studies have provided evidence to support this view (14). If people refrain from taking the tests, if they choose ignorance, they might fail to obtain medical help which would improve their probability of survival. Consequently, there is strong opposition to the disclosure-only approach, particularly by medical associations and public health authorities.
- It is true that people will have the option of taking out insurance prior to taking any genetic tests. However, this is not always a practical solution. Firstly, some people may be given genetic tests while they are still children. Secondly, tests taken by one member of a family might have implications for the availability of insurance to other members of the same family.

Professor Tabarock has offered one possible solution. People taking genetic tests may be required to purchase “genetic insurance” (36). If the genetic test revealed a potential health problem, the insured person would receive a sum sufficient to cover the extra premium required to purchase life or health insurance. This would set in new challenge for insurers, who would need a considerable degree of expertise to set the appropriate premium for genetic insurance.

2.3. A Ban on Using Genetic Information in Underwriting

The third approach is more comprehensive - we can introduce legislation to prevent insurers from using any genetic information in the underwriting process. Even if the applicant has been tested, the applicant would not be required to disclose the results.

Insurers point out that this will provide the opportunity for adverse selection by those who have taken genetic tests, thus endangering the solvency of insurers. They argue that in the long run, this will reduce availability for some types of insurance. For example,

“It is difficult to see insurers enthusiastically entering into the long term care insurance market if proposers might know that they had a genetic predisposition to Alzheimer’s disease, with the relevant genetic information not available to the insurer” (1)

Also, if adverse selection occurs, this will lead to an overall increase in premium rates. An American insurer has attacked a Minnesota proposal to ban testing:

“This [proposal] is anti-consumer. If insurers are not able to have access to the people’s medical background to classify risk... over time the price of the product is bound to go up.” (29)

On the other hand, some argue that the possible impact of adverse selection has been overstated, particularly in relation to life insurance. Peter Harper, for example, suggests that :

“Life insurance companies could, with little loss, forgo the use of genetic testing results other than in exceptional circumstances, and the industry could indeed benefit from avoiding the need to assess an increasing volume of complex and largely irrelevant data.”(3)

A UK actuary, Angus MacDonald, has provided a most useful analysis of the potential financial impact of adverse selection in the life insurance industry (12). He identifies a number of variables which are significant, including:

- the proportion of the population which has a genetic defect
- the financial significance of the defect, i.e. to what extent it causes early death
- the proportion of the population which is insured
- the proportion of the population which takes a genetic test
- the rate of adverse selection, i.e. the extent to which people with a known risk factor are more likely to buy insurance
- the extent to which adverse selectors also insure their lives for higher amounts

For example, if the number of people with genetic defects is relatively small, relative to the number of insured lives, then the impact of adverse selection is reduced: a small increase in premiums for all would cover the extra cost of claims for the few. MacDonald uses a Markov model to estimate the financial impact of these variables, and comes to the following preliminary conclusions (12):

“The figures above are illustrative only, but they suggest the following tentative conclusion. If life insurance companies refrain from using (or are forbidden to use) the results of any genetic test in underwriting, additional mortality costs are likely to arise. However, if adverse selection does not extend to untypically large sums insured, the magnitude of these costs is greatly reduced; large sums insured is the costliest aspect of adverse selection.”

Hence, it might be possible to limit the impact of adverse selection by limiting the sums insured available without testing. That is, insurers would be required to provide a certain amount of insurance at standard rates without any genetic tests - any excess would be subject to genetic underwriting. This approach has been adopted in the UK (on a voluntary basis, for some types of insurance) and in the Netherlands (by legislation).

There are other alternatives, which may be helpful in reducing the impact of adverse selection. Insurers might be protected by a reinsurance pool. The following suggestion was proposed in the UK, in a submission to a government committee (11)

1. Insurance contracts should not ask for any information on genetic tests at the time the contract was made
2. If the insured dies of a genetic disease on a list maintained by an appropriate authority as predictable by a genetic test, then the sum paid by the insurance company need not exceed a ceiling specified at the time of the contract
3. Insurance companies would re-insure in an industry pool against the risks of deaths from genetically identifiable causes on the list.

The UK House of Commons Committee concluded that (11):

“The evidence given to us ... suggests that it would be possible to find ways to regulate the use of genetic information in insurance which would protect both the interests of society in enabling as many people as possible to obtain insurance and protect the insurance companies themselves.”

Actuaries are now working to try to develop practical solutions, which will meet the needs of society while still maintaining a financially sound insurance system.

2.4 Summary

On one side, insurers argue that there is no need for regulation of genetic testing in insurance. They argue that any regulation would be detrimental to insurers. Insurers might become insolvent; might be forced to charge higher premiums; might refuse to sell some types of policy. Hence regulation would adversely affect consumers as well as insurers.

On the other side, there are numerous advocates for greater regulation: doctors, medical researchers, bioethical experts, public health authorities, privacy commissioners, and those with a family history of genetic defects, all strongly oppose the use of genetic testing by underwriters.

It must be admitted that public opinion tends to support the latter view; irrational as it may seem to some, it appears that the general public is overlooking the arguments of actuaries, ignoring the financial interests of insurance companies, and showing a stubborn desire to protect the interests of those who may be afflicted with serious illnesses.

“The American Council of Life Insurers survey found that about 80% of respondents said that insurers should not have access to any type of genetic test results, regardless of why, where, or when such tests were done” (8)

A 1992 survey found that 41% of the American public thought that no one other than the subject deserves to know that he or she carries a defective gene. Less than 30% thought that an insurer should have the right to know. (21)

Almost 8 out of 10 people in Britain are opposed to insurance companies using genetic test results as the basis for charging higher premiums or refusing to

provide cover, according to an opinion poll commissioned by the Genetic Forum”(31)

Now it may be simply a matter of education - perhaps the general public does not understand the issues. Chuffart (52) refers to:

“The rather emotional public perception of genetics, exacerbated by ignorance, erroneous opinions and unfavourable prejudices....(and) the public’s lack of knowledge of the principles of insurance. It is astonishing to notice the fundamental ignorance in insurance matters not only of the average consumer but also of the best educated people and the legislators.”

On the other hand, it is possible that the public does in fact understand the issues, but is willing to accept the negative consequences. The fact remains that in some countries the government has decided that public interest requires intervention to protect those with genetic defects - whatever difficulties this may cause for insurance companies.

2. INTERNATIONAL REGULATORY DEVELOPMENTS

The following section summarises developments in regulation in the United Kingdom, Europe, the United States, Australia, New Zealand, and Canada.

In brief :

- In the UK, there has been a considerable amount of public debate; there is a strong lobby in favour of regulation. The insurers have adopted a voluntary code in an attempt to stave off government intervention in the insurance industry.
- In the European Community, several countries have already introduced comprehensive restrictions on genetic testing, and it appears likely that other countries will follow suit. In some European countries, the insurers have adopted voluntary self-regulation.
- In the USA, there are already considerable restrictions on the use of genetic testing in health insurance, and the level of regulation is likely to increase in the near future. A few states have introduced legislation controlling life insurance as well, but at present it appears that the life insurance industry has managed to resist such developments with some success. However, a number of consumer groups and medical associations are very active in advocating further legislation.
- In Australia, there is no legislation. This paper includes a summary of comments from the Privacy Commissioner, the Life Insurance and Superannuation Association, and the Institute of Actuaries of Australia.
- In Canada, there is no legislation at present.
- In New Zealand, the Human Rights Commission has issued interim guidelines dealing with this issue. The matter is under review.

3.1 GENETIC TESTING IN THE UNITED KINGDOM

The Nuffield Council on Bioethics

The Nuffield Council on Bioethics was established in 1991, to consider ethical issues arising from biomedical research. Its first project was an investigation into the ethical aspects of genetic screening. A Working Party was established, consisting largely of medical experts and public health authorities. The Working Party published a report in December 1993 (49).

The Working Party noted that genetic testing in health insurance was not an issue in the UK, since health care is provided under the National Health system. However, they were concerned about the impact of genetic testing in life insurance - in particular, they were concerned that the use of genetic testing might sharply increase the percentage of people who would be unable to obtain insurance. The availability of insurance is particularly important for home buyers: in the UK, people are often required to purchase insurance when they borrow money to purchase a home - in the event of death, the sum insured is used to repay the loan.

“For most people in the UK, life insurance is normally linked to home purchase and the covering of basic family responsibilities. It is therefore of great importance to individuals that they are not excluded from life insurance... If large groups of people categorised by genetic conditions were to become effectively excluded from life insurance, then there would be serious consequences for public policy (including, possibly, for social security).”

The Working Party was also concerned about the possible misuse of genetic data, on three counts:

- there was still a great deal of uncertainty about the value of genetic tests, and insurers might tend to be over-cautious in their assessment of risks
- insurers might mis-interpret the data (they cited the US sickle-cell examples)
- there were concerns about confidentiality of genetic information, in particular that it might be disclosed to employers

The Working Party consulted with the Association of British Insurers (ABI). The ABI stated that:

“The UK insurance industry does not intend to ask proposers for life insurance to undergo screening for genetic information within the foreseeable future, but where individuals have had a specific genetic test as part of their medical assessment these tests will fall into the same category as other medical tests and will need to be declared on proposal forms.”

The Working Party made the following recommendations:

- genetic testing should not be made a prerequisite of obtaining insurance
- there should be early discussions between the government and the insurance industry

- pending such discussion, British insurers should impose a temporary moratorium, refraining from asking about the results of previous genetic tests, except where:
 - there was a family history of a genetic disease
 - the sum insured was large

The Report of the Science and Technology Committee

In 1994, the House of Commons Science and Technology Committee (the Committee) commenced an eight-month inquiry, which attracted 161 submissions and involved over 12 public hearings (45). In July 1995 the Committee produced a report entitled Human Genetics: The Science and its Consequences (39). Section VII of this report dealt with genetic discrimination in employment and insurance.

The Committee covered many of the same issues, which had been raised in the Nuffield Council Report. The Committee agreed that genetic testing in health insurance was of relatively little importance in the UK at present, because the National Health Service provided high quality health care without direct charge. However, the availability of life insurance was a matter of concern, since life insurance was often needed to obtain a home loan.

The Committee also agreed with the Nuffield Council, about the possibility of misuse or misinterpretation of data. Some of their witnesses complained that even at present, insurers were not able to interpret the relatively simple genetic information available to them: how would they deal with more complex tests? The witnesses referred to several cases where genetic information had clearly been misinterpreted. Some were concerned that insurers might over-react to the mention of a genetic test on a proposal form, particularly in the early stages of development, when the significance of such tests was unclear. (This may reflect past experience in relation to AIDS risks - some insurers had refused to provide cover to people who had been tested for HIV, even when the test results were negative).

The Committee noted that the insurers, in the main, were sanguine about future developments. The Committee did not agree, accusing the insurance industry of “undue complacency”:

“We cannot see into the future; it may be that the ABI is correct, and that the use of genetic information in insurance is limited, and raises no new problems. However, the great majority of our witnesses, including those with expertise in genetics, think that such information could have major implications for the industry in a relatively short time. In our view, the ABI has reacted to these predictions with undue complacency; it would, at least, be prudent to have contingency plans in place to ensure that changes were dealt with in an orderly manner.”(39)

The Committee recommended that “the insurance industry be allowed one year in which to propose a solution acceptable to Parliament, and if it fails to do so a solution should be sought, by legislation if necessary.”(39)

Also, the Committee recommended the establishment of a Human Genetics Commission, which “would be able to monitor developments in genetics and give advice to the government on the implications of such development across a wide field.” This Commission would be responsible for regularly monitoring the effect of genetic testing on the insurance market, and proposing regulation if necessary.

The Government Response to the Select Committee's Recommendations

The government opposed many of the key recommendations of the Committee, “favouring a minimalist approach involving self-regulation instead of legislation” (42). The following views were expressed in the government’s response (48):

- There appears to be little early prospect that there will be a major increase in the number of (new) genetic tests of potential use to the insurance underwriter.
- There have been isolated cases where insurers have treated genetic information inappropriately, but there is no evidence that this has been widespread.
- The insurance industry’s attitude was found to be responsible
- The government does not believe that legislation would be appropriate now or in the foreseeable future.
- The government does not agree that a deadline should be imposed on the insurance industry for the development of an acceptable solution on the use of genetic information for insurance purposes.
- The government very much welcomes and encourages the dialogue taking place between the ABI and leading geneticists, with a view to correctly identifying problems and exploiting common ground on solutions. Hopefully these discussions will lead to the development of an industry-wide code of practice. The government hopes to see substantial progress within 12 months.
- The government will keep in touch with the above development and will later review whether it needs to take action.

An Advisory Committee on Genetic Testing was established, but it had a narrow scope, covering medical standards but excluding privacy issues, employment and insurance.(42)

This weak response drew “a storm of protest”; in particular, members of the House of Commons Science and Technology Committee complained that the government had thoroughly diluted their proposals (46).

Self-regulation in life insurance : The ABI Policy

The Association of British Insurers (ABI) is an association of 440 insurance companies in the UK; the members of the ABI account for almost 100% of the life insurance and pension business written in the UK(39). The ABI realised that self-regulation was desirable, in order to avoid externally imposed regulation. In early 1997 the ABI issued a policy statement on Life Insurance and Genetics:

“The life insurance members of ABI have decided :

- *They will not continue to ask people to take genetic tests when applying for life insurance*
- *For new applications for life insurance of up to a total of 100,000 pounds, which are directly linked to a new mortgage for a private dwelling being acquired for occupation by the live/lives to be assured, the results of any genetic tests will not be taken into account by the insurance company, if they are to the detriment of the applicant. As at present, account will continue to be taken of family history and of other medical information.*
- *For new applications for other life insurance policies, individual companies will decide whether or not they wish to take account of the results of genetic tests previously taken.” (94)*

In this case, genetic testing is defined as “an examination of the DNA pattern to find out if it differs from normal. In the insurance context a genetic test is one which is regarded as predictive in an asymptomatic individual.”(94)

This policy will apply for two years, until March 1999. It will be reviewed in 1999 to take account of current and likely future developments. Insurers will consider collecting and collating information (subject to strict confidentiality requirements) in order to help informed policy discussions in the future. the information collected will include type of test and the size of the sum insured. The ABI has set up a Genetics Committee, which will produce a Code of Practice for the use of genetic information (including privacy issues).

The ABI policy has been criticised by the National Consumer Council: the NCC claims that the policy could lead to “an ever-increasing ghetto of uninsurable people...People with inherited diseases and their descendants could be denied cover, and the idea that insurance is about pooling risk would fly out of the window”. (50)

The British Medical Council has also criticised the ABI policy; the BMA is concerned that genetic information, which can be extremely complex, could be mis-interpreted. The BMA also commented that:

“We remain worried about the increasing use of people’s health information for non-health uses and would be concerned if people were discouraged from finding out more about their health needs because of fears about the social implications of taking a test.”(50)

Not all British life offices will adopt the ABI policy - according to newspaper reports, a growing number of companies are adopting more lenient policies. (50) To some extent, this appears to be a response to public opinion. Some of the companies are concerned that the use of genetic data by insurers is damaging the industry’s reputation. (50,51). One company, Standard Life, has stated that it will not ask for the results of any genetic tests - the marketing manager points out that “Not having the results of these tests isn’t a financial threat to Standard Life, and is unlikely to be a financial threat to other insurers.”

Genetic Discrimination in Employment and Insurance: The Disability Discrimination Act 1995

As noted below, in the USA the law forbids genetic discrimination in employment, under the Americans with Disabilities Act of 1990. In the UK, the Disability Discrimination Act of 1995 forbids employers from discriminating against those who are disabled. However, the definition of disabled does not cover discrimination against those who are asymptomatic, even where there is a genetic predisposition to an illness.

“A number of unsuccessful attempts were made during the legislative process to include within the category of “disabled person” individuals who had undergone a medical test which indicated that they had a predictive propensity to develop an impairment at a later date (such as Usher syndrome, Huntington’s chorea, Alzheimer’s disease or multiple sclerosis). The Government consistently and successfully resisted such attempted amendments.” (43, p 37)

The Minister explained that:

“We recognise that there is a need to protect people where the effect of the condition is not yet substantial but is expected to be so in the future. That is why the [Act] specifically includes people with progressive conditions as soon as there are any effects in their ability to carry out normal day-to-day activities. However we do not believe that it would be right to include people with conditions which remain latent, possibly for a considerable number of years...The Disability Discrimination [Act] is designed to protect people who have, or have had, an actual disability. ...If we extend it to cover people who may develop a disability at some unspecified time in the future we will undermine the effectiveness of the [Act] by creating uncertainty about who is covered.” (44)

The Act also deals with insurance: “fair discrimination” is allowed, i.e discrimination is justified as long as this is justified by actuarial evidence. The Government has promised to monitor the situation and make regulations where necessary.

“While it would not be lawful always to refuse to provide life assurance policies to persons with a disability, it might be lawful, based upon actuarial evidence, to assess the premium for such a policy in a manner commensurate with the underwriting of risk. However the Government recognised that disabled persons do face discrimination when seeking insurance cover. It intends to approach this question through regulations (backed by guidance and codes of practice) to be made after consultation with the insurance industry and groups representing the interests of disabled people. The Government intends to monitor the Australian experience with regard to insurance under that country’s federal Disability Discrimination Act 1992.” (43, p 129)

3.2 GENETIC TESTING IN EUROPE

A paper by Andre Chuffart (52) provides a useful summary of developments in the European Community. The following information is largely based on this paper, written in 1995, updated where information was available. (Note that there may have been further developments, given the rapid pace of change in this area).

Council of Europe

The Council of Europe is an inter-governmental organisation, set up in 1949, which includes representatives from 38 European countries. It aims “to protect human rights and seek solutions to problems facing European society” (52, p 26). In 1992, the Committee of Ministers of the Council produced recommendations for genetic testing in insurance :

“Insurers should not have the right to require genetic testing or to enquire about results of previously performed tests, as a pre-condition for the conclusion or modification of an insurance contract” (53)

More recently, the Committee of Ministers published the Convention on Human Rights and Bio-medicine. Any country which ratifies this convention is bound to pass its own legislation to implement the requirements of the Convention. This Convention states that

Article 11 :

Any form of discrimination against a person on the grounds of his or her genetic heritage is prohibited.

Article 12 :

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

This appears to forbid insurers from requiring an applicant to undergo a genetic test. It leaves open the question of an insurer’s use of previous test results - would this be considered to be “discrimination” under article 11 ? (60, section 3.14 to 3.15)

Belgium

In June 1992, Belgium introduced legislation to prevent the use of genetic data in insurance. The law simply states that genetic data cannot be transmitted from the policyholder to the insurer (54). This approach ensures that policyholders with favourable test results cannot obtain lower rates as “preferred lives” - hence it will prevent insurer from “cherry-picking”.

Article 5 : Obligation to declare

“The policyholder is obliged to declare exactly, at the time of completing the contract, any particulars known to him/her which he/she could reasonably be expected to

consider as constituting risk assessment elements for the insurer. However he/she does not have to disclose details which are already known to the insurer or which the insurer should reasonably be expected to know. Genetic data cannot be transmitted.

Article 95 - Medical Information

The physicians nominated by the insured shall submit to the insured, at his or her request, the medical certificates necessary for the completion and execution of the contract. The medical examinations necessary for the completion and execution of the contract are only to be based on past medical history establishing the insurance applicant's present medical state and not on genetic analysis techniques capable of determining his or her future state of health.

France

In France, legislation was introduced in July 1994, which stated that “The genetic study of an individual's characteristics can only be carried out for medical purposes or scientific research”.

(55). This law is to be reviewed after five years, in 1999.

At the same time, the French life insurance industry announced that for the next five years, they “would not use any genetic information when determining the applicant's insurability, even if favourable genetic information was brought by the applicant himself.”(56)

Austria

In July 1994, Austria introduced a law banning the use of genetic information in insurance, effective 1 January 1995.

“It is forbidden for employers and insurers, including their representatives and employees, to obtain, request, accept or in any other way make use of the results of genetic analyses on their employees, candidates, policyholders or insurance applicants” (57)

Norway

In August 1994, Norway also passed legislation banning the use of genetic information in insurance. The law states that genetic tests may only be performed for medical diagnostic and/or therapeutic purposes.

“It is forbidden to request, receive, retain or make use of genetic information concerning a third person if such information is the result of a genetic test. It is forbidden to try to ascertain whether a genetic test has been performed” (58)

However

“Information resulting from a diagnostic genetic test is not subject to the prohibition given above”.(58)

The Netherlands

The Netherlands has a moratorium on genetic testing -i.e “insurers have agreed to abstain from ordering genetic tests of using existing genetic information for policies below a certain level (NLG 300,000). The moratorium was initially introduced for a five-year period in 1990, and in 1995 it was extended.

In December 1994, the Health Council of the Netherlands published a report on genetic screening. The Council was concerned that people might be unwilling to participate in genetic screening programs, because of concerns about the impact on employment and insurance. The Council was concerned about the possibility of new forms of uninsurability, and hence the Council urgently requested legislation, as it considered that self-regulation would not be sufficient. (62)

New legislation has recently been proposed, which would include the following provisions (61):

- insurers would not be allowed to ask questions or order medical tests which constitute a disproportionate invasion of privacy, irrespective of sum insured
- insurers would not be allowed to request an applicant to take medical tests which might indicate that the applicant is suffering from a severe and incurable disease (e.g. HIV infection)
- insurers would be prevented from medically underwriting employees in an employer-sponsored pension scheme

Germany, Italy, Spain, and Portugal

These countries have not yet introduced legislation on genetic testing

3.3 GENETIC TESTING IN THE UNITED STATES

HEALTH INSURANCE

In the United States, the genetic testing debate has centered on the availability of health insurance. In most developed countries, access to health care does not depend on the ability to pay. In the United States, the availability of health insurance may literally be a matter of life and death. Hence, the use of genetic testing to deny coverage is a matter of overwhelming importance to many individuals and families.

As a result, there is a strong argument against the use of genetic testing in health insurance:

“Access to health care is as essential as food and housing. Consequently we believe that health insurance should be viewed as an entitlement without preconditions and that denying health insurance on the basis of genotype or any other predisposing condition is wrong.” (//)

THE ELSI RECOMMENDATIONS

As part of the Human Genome Project, the National Institutes of Health and the Department of Energy set up a Working Group to investigate the Ethical, Legal, and Social Implications of the project (the ELSI Group). This group was composed of “a broad and diverse membership including genome scientists; medical geneticists; experts in law, ethics, and philosophy; and consumers” (71). In 1993, ELSI published a report which included the following recommendations, essentially recommending a ban on the use of genetic testing in health insurance:

“(1) Insurance providers should be prohibited from using genetic information, or an individual’s request for genetic services, to deny or limit any coverage or to establish eligibility, continuation, enrollment, or contribution requirements.

(2) Insurance providers should be prohibited from establishing differential rates or premium payments based on genetic information, or an individual’s request for genetic information.

(3) Insurance providers should be prohibited from requesting or requiring collection or disclosure of genetic information

(4) Insurance providers and other holders of genetic information should be prohibited from releasing genetic information without prior written authorization of the individual. Written authorization should be required for each disclosure and include to whom the disclosure would be made.”(72)

These recommendations were endorsed by the National Action Plan on Breast Cancer and by the National Advisory Council for Human Genome Research (70). The American Council of Life Insurance opposed the recommendations, on the grounds that “it directly conflicts with

ACLI policy in its overall thrust and specific recommendations.” The Health Insurance Association of America adopted a neutral stance.

State Regulation : Health Insurance

Most health insurance in the USA is provided through employer-sponsored group insurance plans. Group plans usually provide cover for the employee and his/her family.

This has some disadvantages for those employees who are in the higher-risk category. Employers might be reluctant to hire such a person, where they suspect that this will lead to higher health care costs. Some employers might offer employment, but exclude the member from the health care plan. When high-risk employees are allowed to join the fund, they might become “locked-in”, i.e. unwilling to change jobs because it may lead to a loss of health cover. (65)

This is particularly a problem in relation to small employers. Large employers can usually obtain health cover with automatic acceptance provisions, but insurers often apply individual underwriting for health care plans run by small employers. Some states have introduced legislation to ensure the availability of health insurance for small groups. In some states, the insurer is required to accept all employees of a small employer, i.e. an employee cannot be excluded by the insurer. Other states set limits on the premium rates, i.e. even if the group contains individuals with higher than average risk, the premiums for the group cannot be varied beyond certain limits (65)

Health insurance is also sold on an individual basis. In some states, there are laws to guarantee availability of insurance to those who are above-average risks. In some states, these individuals are insured through a state-run high-risk pool; in other states, an insurer may be obliged to accept high risks. This approach is called “open enrollment”. (65)

The National Association of Insurance Commissioners pointed out that :(65)

“With the increasing adoption of open enrollment requirements among the states, the utility of genetic information in underwriting health insurance is rapidly disappearing, since open enrollment requires the insurer to accept all applicants, regardless of health status “

Nineteen states have already passed legislation regulating the use of genetic testing in health insurance. The legislation varies widely. Some states impose a complete ban; other allow the use of genetic data as long as it does not result in “unfair” discrimination (i.e. any discrimination must be supported by actuarial data). Several states include clauses relating to privacy, written consent, and informed consent. Some include requirements to encourage genetic counselling whenever a test is required. (70) For those who are interested in the details, the National Association of Insurance Commissioners (NAIC) maintains an up-to-date register of state legislation (which is constantly changing).

At present most states use a fairly narrow definition of genetic testing and/or genetic information, i.e. testing of DNA, genes, genes products, or chromosomes. However there have been proposals in some states to widen the definition, e.g. a bill was introduced in Wisconsin,

to prohibit the use of genetic information derived from a physical examination or family history. (70). In Illinois, a bill was recently introduced to regulate the use of genetic testing in disability insurance or long term care - insurers complained that the definition was so broad that it would prevent the use of many standard medical tests, such as testing for diabetes or measuring cholesterol. (83)

The debate continues, and further legislation is likely. According to the Council for Responsible Genetics, in 1996/1997 twenty states rejected bills which would impose or increase the regulation of genetic testing in insurance and/or employment. Further legislation is pending in nineteen states.(71)

FEDERAL LEGISLATION : HEALTH INSURANCE

The States are responsible for insurance regulation, but the Federal Government makes laws regulating employment. Since health insurance is often provided through employer-sponsored plans, this means that Federal legislation is likely to affect the provision of health insurance.

The Federal Government has already passed one law regulating health insurance, where it is provided under an employer-sponsored group plan. Other laws, with wider implications, have recently been introduced into Congress, and have received strong support.

Discrimination in Employment : The Americans with Disabilities Act of 1990

As explained above, some employers may be unwilling to employ people who have genetic defects, because this might increase health insurance costs. The Americans with Disabilities Act of 1990 states that “employers may not conduct a medical examination or make enquiries of a job applicant as to whether such an applicant is an individual with a disability or as to the nature or severity of such a disability” unless the exam or inquiry relates to the applicant’s ability to perform the job functions. (73)

According to guidelines issued by the Equal Employment Opportunities Commission, the definition of disabilities can include genetic defects (74). However, this has not yet been tested in court.

Although the ADA prevented employers from using genetic information to refuse employment, employers were still able to refuse or limit coverage under an employer-sponsored health plan. In particular, self-funded plans had no restrictions, since such plans are not subject to state insurance laws (they are regulated under the Employee Retirement Income Security Act, ERISA). (71)

Further legislation was considered necessary, to inhibit genetic discrimination in employer-sponsored health plans.

Discrimination in Employer-Sponsored Health Plans: The Health Insurance Portability and Accountability Act of 1996

The Health Insurance and Portability Act (HIPA) (also known as the Kennedy-Kassebaum Act) is designed to ensure access to health insurance coverage for all employees covered by group health plans. It was passed by Congress in August 1996, and is effective for plan years beginning after June 30, 1997 (76).

What are the relevant requirements of the HIPA ?

Where an employer offers health coverage to its employees, it may not exclude any employee, or charge higher premiums to any employee, on the basis of that individual's health status. Health status is defined to include genetic information. (75)

The health coverage may have waiting periods of up to 12 months, for pre-existing conditions - however, genetic information may not be treated as a pre-existing condition unless there is a diagnosis of the condition related to that information. (76)

To make sure that the law does not impose unreasonable risks on the employer, health insurers are required to provide insurance to small employers (with between 2 and 50 employees). Health insurers are not allowed to cancel cover simply because the group has poor claims experience.

Furthermore, employees will be given guaranteed portability of insurance, even when leaving a group plan to take out individual insurance. Insurers are obliged to offer insurance all individuals who meet certain requirements: basically, insurance must be available to any person who had health cover in a group scheme for at least 18 months, who has left their job and is not eligible for any health cover under any other scheme. This insurer must not impose any waiting periods for pre-existing conditions. (76) However, these portability rules do not apply if there has been a "gap" in coverage of more than 62 days, or if the insurer can show that "financial or provider capacity would be impaired"(76).

Effectively, when the ADA is combined with the HIPA, it appear that the result is the provision of health insurance for those with genetic defects, as long as they are covered (or were previously covered for at least 18 months) under an employer-sponsored group health plan. However, note that provision of employer-sponsored health cover is optional, and many small employers do not provide health cover.

Discrimination in Individual Health Insurance : Genetic Information Nondiscrimination in Health Insurance Act of 1997

As at the time of writing, further legislation is under consideration in Congress. The Genetic Information Nondiscrimination in Health Insurance Act of 1997 was introduced in the House of Representatives in January 1997, and a similar bill was introduced in the Senate (sponsored by Representatives Slaughter and Senator Snowe respectively). This bill would extend the requirements of the HIPA, to cover individual health insurance as well as group insurance.

The proposed law is as follows: the plan or issuer may not deny, cancel, or refuse to renew health insurance benefits or coverage, or vary the premiums, terms, or conditions for such benefits or such coverage, for any participant or beneficiary under the plan, on the basis of genetic information, or on the basis that the participant has requested or received genetic services.

In this case, genetic information has been defined as “information about genes, gene products, or inherited characteristics that may derive from an individual or a family member of the individual”. This is a fairly broad definition, which is a matter of concern to some insurers.

This bill has widespread support, from a broad coalition of women’s organisations (concerned about breast cancer), health-care advocates, and representatives of the medical community (81)

President Clinton made a speech on July 14, 1997, in support of this legislation. He stated that:

“It’s wrong for insurance companies to use genetic information to deny coverage...It’s wrong when someone avoids taking a test that could save a life just because they are afraid that the genetic information will be used against them”. (79)

In fact, President Clinton proposed his own legislation, building on the bill proposed by Slaughter and Snowe:

“Today my administration is sending legislation to Congress that will ban all health plans, group or individual, from denying coverage or from raising premiums on the basis of genetic tests”. (79)

According to comments by the President’s Health Care Policy Adviser, Chris Jennings, the bill is attracting bipartisan support. He mentioned that the insurance industry “is not completely on board on this initiative”, but pointed out that similar legislation has been introduced in nineteen states, without causing any significant increase in the level of premiums (80).

The Health Insurance Association of America and the Council for Affordable Health Insurance have both argued against the proposed legislation. They argue that insurers should be allowed to use all medical information to determine risk and set prices - otherwise the insurers might incur losses, which would eventually lead to increases in premium rates. (89)

At present, this bill has been referred to various sub-committees for consideration.

There are several other bills before Congress, dealing with the same issues. Those who are interested in following the progress of the legislation, and similar legislation with respect to genetic testing in insurance, may be interested in consulting web pages on the progress of various bills in the Congress, at <http://www.access.gpo.gov>, or the web page maintained by the Council for Responsible Genetics.

LIFE INSURANCE

STATE LEGISLATION : LIFE INSURANCE

The NAIC Working Party

In the United States, life insurance is usually regulated by the states. Although each state has its own legislation, the National Association of Insurance Commissioners (NAIC) provides a forum for state regulators to discuss the issues. The NAIC makes policy recommendations and proposes “model regulations”; but these are not necessarily adopted by the legislators in each state.

In 1994 the NAIC set up a Genetic Testing Working Group, which reported in 1996. Firstly, they investigated current practices. The Working Group found that insurers were not, at that time, requiring genetic tests as a condition of coverage. But insurers were likely to take account of any previous genetic tests which were included in the applicant’s medical record. (65)

The Working Group sought opinions on the need for regulation of genetic testing, by collecting a number of submissions from interested parties, including insurers, actuaries, and consumer groups. Some of these submissions were subsequently published in the Journal of Insurance Regulation. As expected, there was a wide range of views.

The insurers, represented by the American Council of Life Insurers, vigorously opposed regulation of genetic testing, on the basis any such limitations would “ultimately jeopardize the current private market”. (67)

The American Academy of Actuaries (AAA) also opposed regulation, on the basis that it undermines the process of risk classification. The AAA argued that risk classification helps to reduce the risk of insurer insolvency, provides lower premiums, and prevents adverse selection. The AAA submission concluded that “prohibiting the use of genetic information in the risk classification process could prove detrimental to insurers and consumers alike” (68)

Some consumer groups were strongly in favour of extensive regulation, i.e. banning the use of genetic information by any insurers for any purpose. The Council for Responsible Genetics presented a submission arguing that “Insurance is a publicly regulated activity designed to meet broad community goals” and that the social goal of insurance is to spread risk across the community. (69)

The Working Group included representatives from many different states. Again, divergent views were expressed. Some states have consistently adopted free-market approaches in all aspects of insurance, seeking to minimize regulation, in the belief that this would improve the efficiency of insurance markets; whereas other states have introduced extensive regulation, to achieve social objectives.

Faced with such a diversity of views, the NAIC Working Group found it difficult to reach a consensus on state regulation.

“When the working group originally met, there was substantial discussion over the possible development of a model act or regulation. This substantial discussion resulted in substantial disagreement regarding the advisability, necessity, and even the capability of the working group to come to an agreement on such a model.” (65)

“It quickly became apparent that the members of the working group were polarized in their viewpoints of the appropriate regulatory response to this issue.”(66)

“It was the consensus of the group that now is not a good time to define regulatory policy in a model law, because the field is changing too rapidly.” (66)

This disagreement is reflected in the diversity of existing state regulation.

State Regulation : Life Insurance

As noted in the introduction, in the past some American insurers have misused genetic information, denying coverage on the basis of genetic information, even where this was not justified. In particular, in the 1970s some life insurers refused coverage to individuals carrying a single sickle cell gene - this is a recessive gene, and carriers do not have any symptoms. This unfair discrimination led some states to introduce laws specifically forbidding discrimination against carriers of certain genetic diseases, e.g. sickle cell disease or haemoglobin C traits. Louisiana, North Carolina, and Florida have such legislation.

Other states have adopted broader laws, which prevent unfair discrimination based on any genetic information. But insurers are allowed to discriminate if there is adequate actuarial evidence to justify such discrimination. New Jersey and Montana have adopted this approach. (In fact most states have regulations forbidding unfair discrimination, even where genetic information is not specifically mentioned).

At present, relatively few states have imposed a complete ban on the use of genetic information in life insurance. Several states have already considered such proposals - in several cases, restrictions on life insurance were included as part of a package, along with restrictions on health insurance. The life insurance industry has been forced to argue persuasively, to convince the legislators to drop life insurance from the proposals. (70,92)

The life insurance industry has not been wholly successful. For example, Arizona has recently passed a law (effective July 1997) to prevent life and health insurers from using genetic test results to refuse an application or to determine rates. Insurers may not require a genetic test as a condition of coverage. (64)

In New York, the State Senate has passed a bill which would prevent insurers from refusing to issue life or disability insurance to women who have a genetic predisposition to breast cancer. The bill was passed by the Senate in June 1997, and has been sent to the Assembly for consideration.

The issue is still under debate in a number of states. For example, Massachusetts, New Hampshire, Vermont and Nebraska are currently considering various forms of legislation to restrict the use of genetic testing in life and disability insurance. The Massachusetts bill would prevent life insurers from requiring applicants to take genetic tests. The New Hampshire bill

would prevent life insurers from using any genetic information for life insurance policies with sums insured less than \$500,000. The Vermont bill would prevent insurers from using any genetic information in underwriting. (78) In Nebraska, the legislature is considering a bill that would prohibit the use of genetic information “for any non-therapeutic purpose”, which would include life insurance (84).

FEDERAL LEGISLATION : LIFE INSURANCE

The 1997 Congress will also be considering a bill entitled the Genetic Protection in Insurance Coverage Act, sponsored by Representative Joseph Kennedy. This would prohibit the use of genetic information in relation to life or disability insurance, either when provided by an insurer or provided by an employer on a self-insured basis. Details of this bill (and other bills dealing with genetic testing in insurance) are accessible on <http://www.access.gpo.gov>

3.4 GENETIC TESTING IN AUSTRALIA

In Australia, private health insurance is based on community rating; there is no underwriting for individuals - hence genetic testing is not an issue in health insurance. In relation to life insurance, there has been some public debate, but as yet no legislation restricts the use of genetic information in underwriting - in fact a recent court case has confirmed that insurers have the right to use genetic information in the same way as any other medical data (refer court case WA).

The Disability Discrimination Act

The Disability Discrimination Act (DDA) forbids discrimination against people with disabilities, in the provision of goods and services (including insurance and superannuation). According to HREOC guidelines, this includes people who may have a disability in the future (for example, a family history of a disability which a person may develop in the future). Hence it would cover those with genetic defects.

However, the DDA allows discrimination in insurance, where this is based on reasonable actuarial or statistical data and it is reasonable after taking account of all relevant factors.

The Privacy Commissioner’s Report

In 1994, the Government requested the Privacy Commissioner to prepare a discussion paper on the privacy issues arising from new developments in genetic technology. A report was produced in 1996, which included a chapter on insurance (88).

The Commissioner found that at present, life insurers do not ask applicants for cover to undergo genetic testing, but they do require disclosure of the results of previous tests. He noted that the LISA draft code (described below) recommended against the introduction of compulsory testing. He thought that competition might be expected to impede the introduction of overly intrusive tests: he reasoned that such tests would be unattractive to many people, who could take their business to other insurers. Hence he concluded that:

“For the time being, there seems to be little prospect that Australians will be asked to undergo genetic tests in connection with life or disability insurance.”

The Commissioner outlined the arguments in favour of allowing insurers to use genetic information in underwriting - pointing out that adverse selection might undermine the profitability of insurance companies. He concluded that:

“Clearly the all but compulsory collection of this sort of information is intrusive, but the public interest case for it is strong, provided that the information collected is responsibly managed.”

He stated that most life offices handle information responsibly, but it would be advisable to develop a code of conduct in respect of privacy issues.

Life Insurance and Superannuation Association (LISA)

The Life Insurance and Superannuation Association (LISA) has developed a draft policy on genetic testing - the most recent draft was issued in June 1997.

In LISA’s view, the introduction of genetic testing in insurance is unlikely to lead to a significant increase in the proportion of applicants who are unable to obtain insurance at standard rates. Identification of those at risk will lead to more timely preventative treatments. Improvements in genetic technology will lead to new treatments for dealing with genetic diseases.

LISA argues that insurers must be allowed to have access to the results of previous genetic tests; however, they acknowledge that there are concerns about privacy, misuse of data, and the burden of knowledge associated with compulsory tests. Therefore the association has suggested the following policy for Australian life insurers:

- 1. For the purposes of this policy, genetic tests are defined as “the direct analysis of DNA, RNA, genes, or chromosomes for the purpose of determining inherited predispositions to a particular disease or group of diseases, but excluding DNA, RNA, gene or chromosome tests for acquired diseases”*
- 2. Insurers will not initiate any genetic tests on applicants for insurance*
- 3. Insurers may request that all existing genetic test results be made available to the insurer for the purpose of classifying the risk.*
- 4. Insurers will not use genetic tests as the basis of preferred risk underwriting (i.e. offering individuals insurance at lower than standard premiums rates).*
- 5. When assessing the overall risk associated with a particular genotype (genetic makeup), insurers will take account of the benefits of any special medical surveillance that may be beneficial, early medical treatment, and the likelihood of successful treatment.*
- 6. Insurers will ensure that results of existing genetic tests are only obtainable with the written consent of the tested individual.*
- 7. The results of genetic tests will only be used in the assessment of an insurance application in respect of the individual on whom the test was conducted. The result*

will not be used in the assessment of insurance applications of relatives of the tested individual.

8. Insurers will ensure that strict standards of confidentiality apply to the handling and storage of the results of genetic tests.

9. The results of genetic tests will only be available to the insurer's underwriters and reinsurers. The results will be available to other third parties with the written authorisation of the life insured or in the normal course of discovery during legal proceedings.

The above policy is a draft policy - LISA intends to monitor developments, and review the policy in January 1998.

The Institute of Actuaries of Australia (IAA)

In July 1997, the Risk Classification Committee of the Institute of Actuaries of Australia issued a paper on genetic testing in insurance (91). The IAA agreed with LISA: insurers must be allowed to use the results of prior genetic tests, to avoid adverse selection. However, the IAA acknowledged the importance of public opinion, and in particular the need to avoid misuse of genetic data.

The IAA proposed the following principles:

- 1. Individuals seeking to purchase life insurance must disclose the results of all medical tests including genetic tests that they have undertaken prior to the application for insurance. (Disclosure is not required for group life plans for superannuation funds, where the insurer provides automatic acceptance).*
- 2. Public opinion should determine whether or not life insurers can:
 - (a) request that applicants proposing to purchase life insurance undertake genetic tests; or*
 - (b) inform these applicants that a genetic test is available, and that the results may alter the decision to decline, accept, or modify the terms of their application for life insurance.**
- 3. If public opinion allows life insurers to request that applicants undertake genetic tests, or allows insurers to inform applicants of genetic tests, then life insurers should only do so where:
 - (a) the result of the genetic test is a valid indicator (by statistics or informed judgement) of the underlying risk of the applicant;*
 - (b) the insurer provides appropriate pre and post test counselling**

3.5 GENETIC TESTING IN CANADA

In 1992, the Privacy Commissioner produced a report, entitled “Genetic Testing and Privacy Report” (86) The Commissioner noted that the use of genetic testing might create an underclass of “unemployable, underemployed, and uninsurable” Canadians, and recommended further studies. (85)

The Commissioner also noted that Canadian insurers do not usually require insurers to undergo genetic testing; they do require insurers to disclose the results of such tests. He commented that “the insurance industry considers genetic testing to be too intrusive to adequately assess an individual’s potential insurance risks but is closely following the issue”. (85)

At present, there is no legislation, at provincial level or at Federal level, which regulates the use of genetic testing in insurance.

3.6 GENETIC TESTING IN NEW ZEALAND

The Human Rights Act 1993 prohibits discrimination in the provision of “goods, facilities, or services”, including insurance.

In April 1997, the Human Rights Commission has issued guidelines for insurers. These guidelines state that (82):

“Insurance companies can request that existing genetic test results are made available for the purpose of classifying a risk, but cannot insist that applicants undergo genetic tests.”

The Commission notes that this is consistent with the current practice of insurers.

However, the Commission also notes that:

“The situation relating to genetic testing is complex and the Commission proposes issuing further guidelines at a later date.”

4. CONCLUSION

Genetic testing proposes new challenges for insurers, and for legislators who are called upon to regulate insurance companies in the best interests of society. Different countries have adopted diametrically different approaches to the use of genetic information, ranging from a complete ban, to complete freedom. Many countries are still struggling to understand the impact of the new technology, and work out an appropriate response.

In order to assist this process, we suggest that it would be worthwhile to :

- (a) develop mathematical models for assessing the impact of potential adverse selection;

(b) monitor developments in those countries which have introduced restrictions on the use of genetic testing, to determine the extent of adverse selection for different types of insurance, and the financial impact on insurers and customers;

(c) monitor developments in those countries which allow insurers to use genetic information, to determine whether this leads to an increase in the percentage of people who are refused insurance (and in particular, any cases where genetic information is misused);

(d) encourage informed debate on these issues, and survey public attitudes regarding the acceptability of risk classification which is based on genetic information.

This will provide the information necessary for legislators to make informed decisions in the face of conflicting views.

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