

Chapter 7

Insurance

Introduction

- 7.1 The subject of genetic screening in relation to insurance is not new. In 1935 R A Fisher addressed the International Congress of Life Assurance Medicine on the topic, noting that “linkage groups should be sorted out, in order to trace the inheritance and predict the occurrence of other factors of greater individual importance, such as those producing insanity, various forms of mental deficiency, and other transmissible diseases.”¹ However, it is only during the past few years that molecular techniques have provided the opportunity to realise this goal. We are now seeing rapidly increasing numbers of serious disease-causing genes mapped and isolated, with a corresponding ability to predict or exclude their presence in family members at risk and in the general population.
- 7.2 At present, much of our experience of the insurance-related ethical issues comes from Huntington’s disease. This dominantly inherited disease is rare (affecting less than 1 person in 10,000), of late onset and can be predicted with a high level of certainty. Nevertheless, many of the issues it raises also apply to other diseases which may have a genetic basis.
- 7.3 Insurance is unlikely to create any new ethical issues in connection with genetic disorders whose symptoms are already manifest at the time of application. Standard insurance proposal forms have for many years asked about recent medical treatment as well as relevant elements of family history. Insurance companies already require applicants to give consent to the companies’ access to medical records. These records may now, and will increasingly in the future, include the results of genetic screening. New ethical issues are most likely to arise as testing for late onset disorders becomes more widespread, and as genetic screening increasingly identifies individuals with a predisposition to develop certain diseases, though they will not necessarily know of any relevant family history.

7.4

As this report has emphasised, a genetic predisposition to disease is not always an indication of future ill health. The probability that a disease will develop can vary greatly. It may also be very difficult to predict for any given individual the age at which a disease is likely to become manifest. Any prediction is further complicated by the fact that environmental factors often play a major role in many late-onset diseases. Thus, in some cases it will be particularly difficult, if not impossible, for insurance companies to calculate the chance of an individual developing a disease, especially when little is known about its cause, and where statistical information is limited. Huntington's disease, for example, lies at the extreme end of a spectrum. It is a dominantly inherited disease where there is a high level of probability that those having the defective gene will develop the disease. On the other hand, in familial hypercholesterolaemia, another dominantly inherited disease, by no means all of those with the gene will develop coronary heart disease at an early age, and environmental factors such as diet, smoking and exercise may play a major part.

7.5

Although the treatment of some genetic disorders (for example, cystic fibrosis) may increase their frequency in later life, treatment of others (for example, phenylketonuria) has removed the associated disability, while the birth incidence of many other genetic disorders amenable to genetic testing (for example, thalassaemia and Tay-Sachs disease) is falling. This is occurring because significant numbers of families have used the information made available by these tests to avoid the birth of affected children. Thus the introduction of genetic screening may actually decrease the burden to insurance companies; a factor that needs to be taken into account by the insurance industry. It is likely that in the future, as genetic screening becomes more widespread, such a reduction will continue. But this depends on encouraging the acceptance of genetic screening. This will not occur if families are penalised in insurance matters.

Life insurance and health insurance

7.6

Insurance of all types is based on the complementary principles of solidarity and equity in the face of uncertain risks. In insurance, solidarity has been taken to imply the sharing by the population, as a whole or in broad groups, of benefits and costs; while equity has been taken to imply that the contribution of individuals should be approximately in line with their known level of risk.

- 7.7** Life insurance and health insurance are the two forms of insurance to which genetic screening is most relevant. Their relative importance varies between different societies. In the UK, where only a minority of individuals currently depend on private health insurance, health insurance is less important than in countries such as the USA, where it is the principal means of paying for health care and, increasingly, has become employer based. In the future, the largely American concern with health insurance in relation to genetic testing may need to be taken into account in the UK, but the need for this consideration would become serious **only if** there should ever be a major shift in the balance of health care costs from the public to the private sector.
- 7.8** 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, and it is to this form of insurance that genetic screening has most relevance. The issue goes wider than the concerns of individuals. 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).

Different viewpoints

- 7.9** Those applying for insurance, the insurance companies, and professionals in medical genetics, see the issues raised by genetic screening from different perspectives. Each group has valid concerns.

The applicant's viewpoint

- 7.10** Applicants are likely to have the following concerns:-
- (i) pressure to be screened for genetic risk when seeking to obtain basic life and health insurance;
 - (ii) demands for disclosure of existing test results;
 - (iii) refusal of cover or premium increases out of proportion with the risk detected; and
 - (iv) fear of possible divulgence of test results to third parties.

- 7.11 **Pressure to undergo genetic testing** when seeking to obtain insurance is an important issue. It is difficult to assess in the UK the degree to which it is currently affecting individuals' decisions to undergo screening or how it might do so in the future.
- 7.12 The **need to disclose results** of genetic tests that are being or have been done for reasons entirely unrelated to insurance is an issue of great concern. This would particularly be the case in population screening programmes where there is no specific family history. There is the fear that such disclosure, whether by the individuals concerned or their doctors, would make insurance difficult or even impossible to obtain.
- 7.13 A further concern is that insurance might be prejudiced by **misinterpretation** of the finding of a harmless carrier state, for example of the cystic fibrosis gene, or by **uncertainty** regarding the significance of the results.
- 7.14 The **storage of genetic information on databases** that may be shared by a number of insurers is another important issue. There is also the fear that such information might reach employers and others.

The insurers' viewpoint

- 7.15 The insurance companies' main concerns are summarised as follows:-
- (i) adverse selection, especially when large sums are insured;
 - (ii) competition between companies; and
 - (iii) the avoidance of unnecessary discrimination and of consequent adverse public opinion.
- 7.16 **Adverse selection** is the foundation of all the fears that insurance companies have in relation to genetic testing. The term relates to the essentially unfair position faced by the insurance company if the applicant is in possession of relevant information that the company does not have, such as the result of a genetic test. Adverse selection is particularly feared by insurance companies when the policy is for an unusually large sum, a situation already experienced in relation to HIV infection.

- 7.17 **Commercial competitiveness** in the insurance industry is intense. Access to the results of genetic screening would be in the insurers' interests as it would enable them to refuse cover, or raise the premiums, of individuals found to be at increased risk. This would in turn enable insurers to offer cover at a lower premium to individuals thought to be at low risk. There is the understandable fear that if one company does not use genetic testing, but its competitors do, the company would lose custom from those shown to be at low risk, while carrying the increased burden of those with an undisclosed high risk. Equally however, companies wish to avoid unnecessary testing, partly on the grounds of medical and administrative work, but also to avoid losing customers.
- 7.18 As far as the **avoidance of unnecessary discrimination** is concerned, the Association of British Insurers emphasises that over 95% of life insurance policies are obtained at standard premium rate, while less than 1% of proposals are declined due to the mortality risk being too high.² The concern is that the widespread use of genetic testing might sharply alter this balance.

The health professionals' viewpoint

- 7.19 Most health professionals share the applicants' concerns, since undue pressure to be screened, inappropriate demands for disclosure of test results, the misinterpretation of results and the breaking of confidentiality all run counter to established ethical practice.
- 7.20 The new element that is introduced by genetic screening is that programmes of benefit to individuals, families and society may be hampered by fears relating to insurance. For example, genetic screening may identify individuals who are predisposed to late-onset diseases which are treatable or avoidable, such as familial colon or breast cancer. It is important that such individuals do not deny themselves the benefits of genetic screening because of concerns about insurance.
- 7.21 Professionals are particularly concerned that the results of genetic testing might be misinterpreted by insurers, with healthy carriers in some cases denied coverage, as happened previously with sickle cell testing in the USA.³ The opportunity for such misinterpretation is likely to increase with testing for greater numbers of disorders, often rare and unfamiliar. The consequences of denial of health insurance may be immense in countries, such as the United States, without a comprehensive

national system of health care; these may also extend to loss of employment, since the majority of health insurance systems are employment based.

Current Practice

- 7.22 The insurers' current practice in dealing with applications is to ask for medical details, including family history, then to ask for the individual's permission for a medical report and examination and for the results of any tests that have been done previously.
- 7.23 Our understanding of the way in which insurers treat information on family history suggests that there is unlikely to be a major difference between declaring a family history and declaring that the gene is actually present. Tables used by the insurance industry show that insurers treat a 5% risk of developing Huntington's disease in the same way as a 50% risk : such individuals may be declined insurance or offered insurance at an increased premium, depending on their age at the time of application. Insurance prospects for individuals with a family history of Huntington's disease only improve when the risk is below 5%.
- 7.24 The Association of British Insurers (ABI) in their submission to us stated their position clearly (a comparable position has been taken by insurance companies in the USA):-

"From the point of view of insurers, genetic diseases can be divided into two main groups. The first is the known genetic diseases such as Huntington's disease, cystic fibrosis or Duchenne muscular dystrophy, for which specific tests are already in use. In these cases the insurance industry already has experience of individuals who have had a genetic test because of a medical history and insurers treat the results of such tests in exactly the same way as the results of any other medical test."

"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."

- 7.25** According to the ABI's position it would seem that there is a clear duty for individuals and their doctors to disclose the results of any genetic test. It could be questioned, however, whether tests carried out in the context of genetic counselling should be regarded as part of 'medical assessment'; such assessment would be expected to involve only those tests relating to past or family history of disease or current illness.

Resolving the ethical issues

- 7.26** It is important that the concerns of applicants, insurers and health professionals be reconciled in such a way that the principles of consent and confidentiality are maintained while at the same time balancing the principles of solidarity and equity. An appropriate balance has also to be found between the public health benefits of genetic screening, the ethical concerns of individuals and the principles of solidarity and equity.
- 7.27** At present, genetic screening or testing is most likely to occur in families with a known risk. Where an individual is aware of a family history of a genetic disorder, good faith on the part of both applicants and insurers requires that this information be declared on insurance proposal forms. Insurers already take into account the risk as determined by the family history when deciding whether to insure and at what premium. As insurers interpret this information cautiously, there is unlikely to be a major difference in insurability between an individual with a family history of a genetic disorder and an individual who has had a positive genetic test result.
- 7.28** If the individual who has a family history of a genetic disorder chooses to have a genetic test and it is positive, we suggest that this result, with the specific consent of the proposer, may be made available to the insurer, but that the insurance decision based on the family history should not be changed. Thus premiums would be the same for individuals who have tested positive for a genetic disorder as for those who have declared a family history but have not had a genetic test.
- 7.29** For those with a negative (ie normal) test result, however, we would expect them to benefit from this information and be granted premiums similar to those without a family history. In this way we hope that applicants will not be deterred by fears relating to insurance from having genetic tests and that insurers, by continuing their present practice based on family history, will not be adversely affected. Both parties should indeed benefit. For example, if there is a family history of Huntington's disease, an

individual may find it impossible to get insurance; if genetic testing is positive, and the result declared, the situation for both parties does not alter. But, if the test is negative, the applicant can be insured and the insurer gets a new customer. If this principle can be accepted, there will be no need for insurers to ask for genetic testing, and the freedom of individuals to decide whether or not to be tested will not be hampered by insurance considerations.

- 7.30** Population screening raises quite different ethical issues, as the majority of individuals participating in such programmes would be unaware of any family history of the disease being screened for. In addition, according to the principles laid out at the beginning of this report (paragraph 3.9), such screening is likely to be offered only if something can be done to reduce the risk following a positive result. The presence of an abnormal gene for a recessive disorder, for example cystic fibrosis, has no effect on the health of the individual concerned. It is not therefore relevant to life insurance companies to be informed about the results of carrier screening for recessive disorders.
- 7.31** If insurers were to demand access to the results of population screening for polygenic or multifactorial disease (for example, for genetic predisposition to breast cancer), and premiums were increased for those who tested positive, many people would clearly be discouraged from participating in such programmes. This could have adverse consequences both for the health of individuals and for the public health.
- 7.32** At present, we have no experience of such discrimination by insurers and indeed their statement indicates they currently have no intention of requesting any genetic testing before insurance. We suggest therefore that, at least for the present and until we have more experience of screening programmes, individuals should not be required to disclose the results of population screening tests when applying for life policies for reasonable sums. This would parallel the moratorium agreed in 1990 by the insurance companies in the Netherlands to run for a trial period of five years.
- 7.33** For unusually large sums, however, insurers should have the right to ask for results of all tests. The exact sums would need to be discussed with the insurance industry and take into account matters such as housing costs. A feature of the moratorium in the Netherlands is that only for sums over the equivalent of £65,000 (200,000 guilders) should genetic screening results be declared.

7.34 If insurance companies are to have access to the results of genetic tests, they must have the ability:-

- (i) to interpret the risk accurately if undue discrimination is to be avoided;
- (ii) to ensure the absolute confidentiality of all genetic test results, because of the concern that interested third parties, such as employers, might gain access to genetic information disclosed to insurance companies.

7.35 We consider that the principle of free and informed consent should not be compromised by insurance considerations. Therefore, genetic testing should **not** be made a prerequisite of obtaining insurance.

Conclusions and recommendations

7.36 Our recommendations about the use of genetic screening and genetic tests by insurance companies follow from the following considerations:-

- (i) the difficulty of assessing what may be slender evidence on the genetic susceptibility of individuals to develop polygenic and multifactorial diseases (for example, some cancers and some heart disease);
- (ii) an awareness that ordinary commercial practice will lead companies to be over-cautious in their assessment of the risks derived from medical data; and
- (iii) the possibility of abuses.

7.37 **We recommend that British insurance companies should adhere to their current policy of not requiring any genetic tests as a prerequisite of obtaining insurance.**

7.38 In the light of the arguments summarised in paragraph 7.36, **we recommend that there should be early discussions between the Government and the British insurance industry about the future use of genetic data, and that pending the outcome, the companies should accept a temporary moratorium on requiring the disclosure of genetic data.** There should, however, be two exceptions:-

- (i) first, in the case of those individuals where there is a known family history of genetic disease that can be established by the conventional questions about proposers' families, then individuals may be asked to disclose the results of any relevant genetic tests (see paragraph 7.28); and
- (ii) the moratorium should apply only to policies of moderate size. The limit would be a matter to be settled between the Government and the industry in the context of arranging the moratorium.

The importance of the discussions that are recommended is highlighted by the considerations set out in paragraphs 7.7 and 7.8.