LIFE INSURANCE ASSOCIATION

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11 May 2005

Dear Professor Kaan

Thank you for inviting the Association's comments upon the consultation paper on the issues raised by the developments in field of genetic science.

The paper highlights the far-reaching impact of these developments upon a wide range of social, ethical and public-policy issues. However, it is perhaps appropriate that I confine my comments to those areas which have specific relevance to life and health insurance.

In paragraph 4.7, the paper acknowledges the fears that disclosure of genetic information could lead to the emergence of a 'genetic underclass' who may find difficulty in obtaining insurance. These concerns are based more on speculation than upon fact but they do, nevertheless, need to be addressed.

In reality, there is little reason to suppose that the proportion of the population that can be accepted for insurance will suffer as a result of advances in genetic science. Historic evidence suggests that advances in medical knowledge have consistently contributed to improvements in mortality and a broadening of access to insurance. We doubt that the development of genetic science will prove to be any different. It is far more likely that a better understanding of the interaction between genetic makeup and environmental influences will, over time, improve the effectiveness of health management and, as a result, lead to further improvements in mortality. If one accepts that premise, there is a clear coincidence of interest between life insurers and society as a whole in the successful development of genetic technology.

We fully understand that the link between genetic profile and predisposition to disease is by no means straightforward - even with many of the monogenic disorders. Certainly, we have insufficient knowledge of the all-important link between multifactorial genetic defects and other behavioural and environmental factors. It may be some time before even those who are specialists in the field of genetics are able to predict, with confidence, the impact of specific genetic defects upon mortality. That being so, insurance companies do not seek, and for the

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foreseeable future would have no intention of seeking, genetic tests as a tool for screening of applications.

Nevertheless, as your paper has identified, one must draw a distinction between the active use of genetic tests as a routine underwriting tool and the more passive requirement to disclose the result of a test conducted for some entirely different purpose. We note that the dilemma that this poses has been put to one side for further study.

We certainly welcome and endorse your Recommendation 8 in which you urge discouragement of the development of genetic testing services outside of the framework of the healthcare profession. For society as a whole, the principal concerns must be for the social consequences of testing without appropriate counseling. However, an additional worry for insurers would be that the information would encourage insurance buying decisions that are inappropriate and based on unjustified fears or, worse still, taken with a view to gaining advantage from information that would not be available to the insurer.

Even where testing is carried out within the umbrella of the healthcare profession, Insurers would have concerns about the potential *longer-term* implications of being denied access to relevant medical history. The foundations of insurance are firmly rooted in pooling of risks but, at the same time, underpinned by attempts to achieve broad equity between premiums and the risk borne by the pool. Discrimination *between,* as distinct from *against,* applicants is part and parcel of the risk evaluation process. An asymmetry of information between the applicant and the insurer opens the risk of an unfair cross-subsidy between individuals presenting significantly different risk profiles. This may be manageable in the short term but could have more serious consequences if – or, more likely, when – genetic technology establishes a place in mainstream medical practice.

We are also mindful that the perceptions and definitions of what constitutes 'genetic information' or a 'genetic test' will change over time. It is recognized that many more conditions have a genetic component than was once thought to be the case. We must, therefore, expect that genetic testing techniques will be used increasingly in the diagnosis of conditions that would currently be identified by clinical means.

Thus, the industry would be very concerned if the *principle* of withholding genetic information were enshrined as a right. Nevertheless, I suggest that there is considerable scope for the Association to work with your Committee to develop interim measures which address the real concerns that you have identified. Furthermore, I would also see mutual benefits in an ongoing dialogue to ensure that, as genetic technology develops, the insurers' response is based on sound ethical and scientific principles and, equally, that public-policy decisions on the use of genetic information do not overlook the genuine interests of insurers and the majority of their policyholders.

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I would therefore very much welcome a meeting with you and/or members of your Committee to explore ways in which the industry can work cooperatively to support your objectives.

In the meanwhile I attach a paper entitled *'Genetic Science and its Implications for Life Insurance'*. This is a paper, of which I was the principal author, published in the Transactions of the International Congress of Actuaries in 1998. It was the result of the studies of a working group formed by the Institute of Actuaries in UK to addresses the issues of equity and access to insurance posed by genetic developments. The opening section was designed for an audience that had little knowledge of genetics and will be of little interest to your committee members. However, you may find the discussion that follows relevant to the issues that you are debating. The science has taken several strides forward since that paper was written and I would, therefore, also commend a more recent paper by Daykin et al entitled *'Genetics and Insurance – Some Social Policy Issues'* which is published in the British Actuarial Journal 2003 Vol. 9.

I look forward to hearing from you if you feel that the Association can help you in framing your final recommendations.

Yours sincerely

John Lockyer
Executive Director

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Genetic Science and its Implications for Life Insurance

By J. Lockyer, P C Brett, S A Hannington, J A N Lockyer, A S Macdonald and J J Woods
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Summary

Genetic science is driven by the prospect of advances in knowledge and medical care, both positive forces. Unfortunately, insurance is widely seen as an impediment, holding back applications because of fears about the consequences for a `genetic underclass'. It is important that the actuarial profession, the insurance industry and other interested parties reach methods of dealing with genetic information that are practical and acceptable to all parties.

First, insurers must understand the implications of genetic disorders. There range from monogenic inherited disorders with very specific outcomes (such as Huntington's disease) or with variable outcomes (such cystic fibrosis) through polygenic disorders which represent one of many influences on the outcome, to non-inherited somatic disorders (such as lead to many cancers).

Striking a balance between workable insurance practice, in which adverse selection is controlled, and acceptable public policy, in which discrimination is not extended unreasonably, will not be easy. At one extreme is the view that the scientific principle of insurance should be upheld, if the purchase of insurance is in any way voluntary. At the other is the view that insurance principles cannot override natural justice. A pragmatist might acknowledge the strengths of both arguments, and ask how much any departure from the unfettered `right to underwrite' might cost. Little information is available to help, as yet. One study, confined to life assurance, suggests that the costs would not be large provided some limits were placed on the sums assured that could be obtained under limited underwriting. No comparable studies have been carried out for health or long term care insurance, where greater problems might be expected.

More research is needed urgently into all aspects of insurance-buying behaviour and adverse selection, as well as the implications of the purely statistical knowledge to be gained from genetic tests. Such research will not be easy, and might require the insurance industry to look beyond the statistics it gathers in the ordinary course of its business, but, in its absence, policy-makers are likely to be more strongly swayed in directions which appear to be supported by relevant research.

Genetic science and its implications for life insurance

La Génétique et ses Applications pour l'Assurance Vie

By J Lockyer, P G Brett, S A Hannington, J A N Lockyer, A S Macdonald and J J Woods

Summaire

Les généticiens sont aiguillonnés par deux forces positives : leur désir de faire avancer les connaissances et celui d'améliorer les soins médicaux. Les assureurs sont, pour leur part, souvent considérés comme des poseurs d'obstacles, freinant la transposition de ces avancées, de crainte qu'elles ne génèrent une "sous-classe génétique". Il est donc temps que les actuaires, les sociétés d'assurances et les autres groupes intéressés mettent au point des méthodes de traitement de l'information génétique qui soient praticables et susceptibles d'être acceptées par toutes les parties.

Tout d'abord, les assureurs doivent bien comprendre l'impact des différentes catégories de maladies génétiques :
- maladies héréditaires monogéniques, présentant des manifestations très spécifiques (maladie de Huntington, par ex.) ou variables (mucoviscidose)
- maladies multifactorielles (en conjugaison avec des facteurs environnementaux)
- maladies somatiques acquises (qui sont la cause de nombreux cancers, par ex.).

Il ne sera pas facile de trouver un équilibre entre des pratiques d'assurance viables permettant de contrôler l'anti-sélection et une réglementation publique acceptable selon laquelle la discrimination reste limitée. Il existe deux points de vue diamétralement opposés : certains considèrent que les principes scientifiques de l'assurance sont à appliquer puisque contracter une assurance est un acte volontaire ; d'autres estiment que les principes de l'assurance ne peuvent primer sur la justice naturelle. Une personne pragmatique peut reconnaître la solidité des deux argumentations et demander ce que coûterait l'abandon du "droit d'évaluer les risques". Pour l'heure, nous avons peu d'informations à ce sujet. Une étude, limitée à l'assurance vie, laisse entendre que les surcoûts ne seraient pas énormes à condition que l'on limite les sommes assurées au moment de la souscription. Il n'existe pas d'études similaires, ni en Maladie, ni en Dépendance, or c'est là qu'on peut s'attendre à des problèmes plus sérieux.

Il est donc urgent d'analyser plus finement ce qui pousse les gens à acheter des couvertures d'assurance, sans oublier les nombreux aspects de l'anti-sélection et l'impact des connaissances purement statistiques que l'on peut tirer des tests génétiques. Cette recherche ne sera pas facile et il se peut que les assureurs soient amenés à exploiter des statistiques dépassant le cadre de leurs affaires quotidiennes. Faute de quoi, le législateur aura plutôt tendance à retenir les conclusions prônées par ceux qui auront fait des recherches pertinentes.

J. Lockyer et al (UK)

1. Introduction

1.1 The authors of this paper are the members of the Genetics Working Party which was established by the Life Insurance Board of the Faculty and Institute of Actuaries in the United Kingdom, the objectives of which were:

- to inform members of the profession, in general terms, about developments in genetic testing
- to discuss the philosophical issues raised
- to examine the practical implications for the life insurance market

This paper is a report on the results of the Group's studies.

1.2 A huge international research effort is currently being directed to the mapping of the human genetic code and to the parallel development of new genetic tests. The pace of these advances, allied to the perceived predictive powers of these new tests, has led to public concern about the implications of this new technology. An area that has attracted considerable comment and attention is the use of genetic information by insurance companies. In particular there is concern that, through ignorance or prejudice, people with genetic defects will not be treated fairly at the hands of the insurance industry.

1.3 This subject is very much at the forefront of the insurance industry's thinking, following the Association of British Insurer's recently published draft Code of Practice and with the Human Genetics Advisory Commission's report on the implications of genetic testing for life insurance due at the end of the year.

1.4 The view that seems to have gained popular support is that insurers should be denied access to genetic information on the grounds that its use would be discriminatory and would affect the rights of those who, through no fault of their own, may already be disadvantaged. It is therefore timely that the Genetics Working Party of the Life Insurance Board has completed this paper.

1.5 Due to the complexities of this subject, this working party has concentrated on the effects of genetics on life insurance. It is the working party's opinion that the conclusions in this paper cannot necessarily be carried over to critical illness, permanent health, long term care or private medical health insurance. For instance, critical illness policies, which pay on the diagnosis of certain conditions, are affected more by the prognostic abilities of genetic testing. The issues involved with these covers are left for a future paper.

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1.6 It is generally accepted that, with the increased understanding of genetics, tests will be developed that will identify a person's predisposition to given genetic conditions. However, what is less certain is the predictive power of these tests or their applicability to the general population. At the one extreme there are those who argue that the sheer volume of genetic information and the complexity of the interaction with environmental factors mean that the ability to analyse and understand the full implications of an individual's genetic profile is a distant dream.

1.7 At the other extreme there are those who foresee the possibility of generally available genetic screening within a generation. The truth is probably somewhere between the two. Currently genetic tests are complex, expensive and only capable of identifying one genetic condition. As a result, they are presently used only on people with a family history of the given condition. Hence, it seems probable that generally available multiple genetic tests are at least a decade away.

1.8 Life insurance depends on the unknown, with people being prepared to insure their lives to cover the risk that misfortune may strike. The degree of certainty that genetic testing will bring to people's understanding of their future mortality poses unique and fundamental questions, especially if its use by the insurers is restricted. As mentioned above, genetic testing will have no practical effect on life insurance for a number of years. One could argue that these questions do not need to be considered just yet but public concern about this issue demands answers now.

1.9 In looking at this topic the working party was conscious that man's power to invent is matched only by his ability to underestimate the potential of what he has developed. Whatever one might say today about the impact of any scientific development will, in all probability, prove to be a gross understatement of the reality that will unfold. This being so, the working party stresses the need for the profession to revisit this topic on a regular basis and to avoid becoming locked into a position, the full implications of which cannot be fully comprehended.

1.10 The structure of the paper follows the working party's aims mentioned previously.

1.11 Chapter 2 gives a brief introduction to genetics. It explains in simple terms what genes are, how genetic conditions are inherited, what types of genetic diseases there are and finally what consequences genetic testing will have for these different types of genetic diseases. It concludes that genetic testing is likely to become a routine tool in medical practice.

1.12 The next chapter describes the political background. It starts with the 1989 resolution of the European Parliament and traces the events that have led to the response from Association of British Insurers' and the review underway by the Human Genetics Advisory Commission. It then looks at how some other governments have taken a tougher line in this respect than the British Government.

1.13 The fourth chapter looks at the philosophical issues posed by conflicting views on the rights of access to genetic information. It examines the reasons for underwriting, points out that, at present, there is no justifiable reason to require an applicant to undergo a genetic test but explores the need for disclosure of genetic tests that have taken prior to application. Finally it questions whether those with genetic disorders should be treated more favourably than someone with another form of disorder.

1.14 The final chapter looks at the necessity to come up with a practical solution which addresses public concern. Referring to the work of Macdonald it concludes that the Association of British Insurers' concessions will not lead to a large increase in the insured lives mortality experience and therefore provides a balance between the concerns of the public and the requirements of the insurers.

2. Understanding Genetics

2.1 Before entering into a discussion of the significance of genetic technology, it will be helpful to define some of the key elements of the genetic lexicon.

DNA

2.2 Deoxyribonucleic acid - DNA to give it its more manageable abbreviation - consists of two intertwining strands made up of four bases; adenine (A), thymine (T), guanine (G) and cytosine (C). Each strand contains sequences of these four bases. Complementary strands pair A with T and G with C so that, for each sequence on one strand, there is a complementary sequence on the other.

2.3 The sequences of the genetic alphabet, A, T, G, and C, are arranged in 'words' of three letters. About 10% of these three letter sequences contain the instructions to produce amino acids which, in turn, combine to form proteins. The remaining combinations of the genetic alphabet along the DNA chain have no recognised function.

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2.4 The equivalent of approximately 2 metres of DNA is packed into each human cell.

Chromosomes

2.5 Chromosomes are paired bodies, in the cell nucleus, which consist of proteins and DNA. Until the 1940s it was not known whether it was DNA or the proteins which carried the genetic code but the prevailing thought was that DNA was far too simple a molecule to carry the complex web of information required to record the blue-print for the control of life form. In 1944 Oswald Avery, a microbiologist, published an article which demonstrated that it was, in fact, DNA, and not the proteins in a chromosome, that carried the genetic code.

2.6 Cells in the human body have 23 pairs of chromosomes - 22 pairs of what are known as 'autosomes' and one pair of sex chromosomes. One chromosome from each pair comes from the mother and the other from the father - each consisting of one long DNA molecule in a tightly coiled strand. The autosomes of the two sexes look identical but the sex chromosomes are quite distinct. Females have two large 'X' chromosomes whereas males have a single 'X' chromosome and a smaller 'Y' chromosome. The 'Y' chromosome has relatively few genes - a fact which, as we shall discuss later, has implications which make males more prone to certain types of inherited diseases.

Genes

2.7 Genes have been described as beads along a string of DNA - each made up of 'sentences' arranged from 'words' from the genetic alphabet. They vary considerably in size, from a sequence of around five hundred letters to something in excess of two million.

2.8 It is estimated that there are about 100,000 genes which control the biological processes in human beings. The location of each gene is fixed and, because chromosomes are paired, genes are also paired. Each gene produces its own specific protein, which has a crucial part in controlling the processes necessary for life. If there is an error in the genetic code the specific protein produced by the affected gene will not function properly and this may cause disease.

2.9 Each cell of the body has the same DNA and therefore the same genes. However, depending upon the gene's ascribed function and the location of the cell in which it is situated, it may be active or 'switched off'.

The Genome

2.10 Originally the word genome was coined to describe the whole body of genes in cell. However, it is now recognised that 90% of the three-letter

sequences in DNA appear to have no direct genetic function. As a result, the meaning of the word has been modified to include all DNA within a cell.

Basic Rules of Inheritance

2.11 The development of genetic science has been closely linked to the study of the rules which govern inheritance. We now understand that it is genetic diversity that explains why we have individual characteristics. Many of these differences are benign but, as we shall see, there are variations in genetic structure that have more serious – even sinister – implications.

2.12 The founding father of genetics was an Austrian Benedictine monk by the name of Gregor Mendel. It was he who discovered the basic laws of inheritance in the mid 19th Century through his study of the garden pea. One of the traits which he studied was how the colour of the peas in the pod passed from one generation to the next.

2.13 He pollinated a yellow pea plant with a green pea plant as a result of which he produced plants which all had yellow peas. These yellow pea plants were then used to pollinate one another. This time the result was a mixture of plants with green and yellow peas in the ratio of one green to three yellow. This led Mendel to propose that each plant has a pair of genes which determine the colour and that, during fertilisation, the pollen and egg provide one gene each which form a pair. The genes, he proposed, were either dominant, in which case only a single copy of the gene is necessary for the trait to manifest itself, or recessive if it takes two copies of the gene for the trait to emerge.

2.14 These are the rules which, indeed, define single gene, or Mendelian disease. There was, however, a further variant which Mendel's experiment had not identified. This next step in the understanding of inheritance came at the beginning of this century and resulted from the experiments of Thomas Morgan. From his study of fruit flies he made the discovery that it was the chromosomes which are present in all cells that carry the genetic information and which, therefore, must contain the genes.

2.15 He found patterns of inheritance that could not be explained by Mendel's rules. One example was eye colour. Fruit flies have either white eyes or red eyes. Morgan found that the eye colour depended on the eye colour of each parent. When white-eyed males were crossed with red eyed females, there were both white and red-eyed offspring. However, when red eyed males were crossed with white eyed females, all of the male offspring had white eyes whilst all the females had red eyes. This led Morgan to the discovery that, in the case of the fruit fly, eye colour is inherited through the X chromosome. A daughter will inherit an X chromosome from both the

mother and father, with the red eye gene being dominant over the white eye gene, but a son would only inherit the X chromosome from the mother and get white eyes.

2.16 It has subsequently been found that this pattern also applies to humans. The Y chromosome carries very few genes and therefore the ordinary rules of Mendelian dominance and recessivity do not apply. Any gene on the single X chromosome will show its effect in a male, whether or not it is recessive in females. This is known as sex linkage.

Genetic Disease

2.17 Any disease, which arises as a result of an error in the genetic code, might reasonably be termed a genetic disease. The term has commonly been held to be synonymous with the single gene or monogenic disorders. The reality is, as Dr Francis Collins of the National Center for Human Genome Research is reported to have observed, "all disease except trauma is genetic".

Monogenic Disease

2.18 There is a range of known disorders which arise from a mutation of a single gene. These are the monogenic disorders of which Huntington's Disease is the most commonly cited example. Huntington's is an *autosomal dominant* disease which means that the defect is in a gene located on one of the autosomes (in this case on Chromosome 4) and that it requires only one of the pair genes to be defective for the disease to manifest itself.

2.19 Autosomal recessive diseases are those which require both genes of a pair to be mutated. This will occur if the mutation is transmitted from both parents. If only one gene has the mutation, the disease will not manifest itself but could be passed on to any offspring. Cystic fibrosis is an example of such a condition.

2.20 The sex-linked diseases occur where a mutated gene located on the X chromosome causes disease in males even though the same condition is recessive in females. This occurs because no paired gene exists on the Y chromosome and thus the mutated gene effectively dominates. Examples are colour blindness, haemophilia and muscular dystrophy.

2.21 In some cases there is a straightforward correlation between the disorder and a specific genetic defect. However, the abnormalities leading to other monogenic diseases may be more difficult to unravel. Cystic Fibrosis, for example, is not characterised by a unique mutation. 70% of sufferers do share a common mutation of a particular gene but the absence of that particular abnormality does not guarantee freedom from the disease. There are over 500 known mutations which might lead to a similar outcome.

2.22 Yet more confusingly, certain conditions can arise from mutations to one of a number of different genes. Alzheimer's disease is an example where various forms of the condition can be traced to mutations to different genes.

2.23 There is not absolute correlation between the inheritance of a genetic profile which is indicative of a monogenic condition and the incidence of disease. The likelihood that the disease will manifest itself is described by the *penetrance*. Huntington's is an example where the penetrance is at or near 100%. Not all monogenic defects confer the same degree of certainty but most carry a high probability that the condition will occur.

2.24 There is a danger that initial studies tend to overestimate the penetrance of a particular genetic abnormality. This tendency arises as a result of the fact that most studies have been conducted by observation of individuals and families where there is a history of the particular condition. It is now recognised that, in the wider population, there may be others with the same genetic mutation but who also have a compensating factor somewhere within their genetic makeup.

2.25 The monogenic disorders also vary in their *expressivity*. This term is used to express the extent to which the severity of the disease, when and if it manifests itself, may vary. Cystic fibrosis again serves as an example. The condition can present symptoms ranging from mild to severe.

Chromosomal Disorders

2.26 Another category of genetic disease, the chromosomal disorders, arise, not from mutations, but where material is either added to or missing from a chromosome. Symptoms become apparent at an early age and, in common with many of the monogenic disorders, these conditions are only infrequently encountered amongst applicants for life insurance.

Polygenic or Multifactorial Disorders

2.27 These are complex genetic disorders which arise from the interaction between mutations to a number of different genes and which may be strongly influenced by environmental factors.

2.28 They indicate an increased susceptibility to a particular condition rather than an omen of inevitability and, in many respects, genetics technology is merely confirming and extending through molecular biology what had been concluded from general or clinical observation. It has long been understood that the secret of a long and healthy life is careful selection of one's parents! The familial link in a number of adult disorders had been recognised without the aid of genetic science even though the cause may not

have been understood. Despite the lack of any clear pattern of inheritance, the tendency for heart disease, obesity, hypertension, and a host of other ailments, to run in families is not a newly recognised phenomenon.

2.29 The interaction of the underlying genetic abnormalities – mutations which may affect a number of genes – and other behavioural or environmental factors is less than perfectly understood.

Acquired Genetic Disease

2.30 Lastly there are the acquired, or *somatic* genetic disorders. These arise where mutations occur in one or more cells which were perfectly normal at birth. The genetic makeup of a particular cell may be damaged by an external environmental factor, such as exposure to cigarette smoke or ultraviolet light or, perhaps, through a fault in the process of DNA replication. The resulting mutation then replicates itself by the normal process of cell division. The common cancers are the most obvious examples. Acquired genetic disease is not usually passed on to the next generation.

Genetic Testing

2.31 Genetic tests may be used to detect a range of known monogenic disorders. These tests offer the capability to identify monogenic diseases before there are any physical symptoms. This raises sensitive ethical questions because the results can have consequences, not only for the individual, but also for other members of the family and even for an unborn generation.

2.32 Tests may also be used to detect acquired or somatic diseases during their presymptomatic state. Unlike the other forms of genetic abnormality, which can be detected from any sample of DNA, somatic diseases may only be detectable from certain localised sites. In that sense, these tests may not conform to the popular conception of what is meant by a genetic test although the technology may be similar. By contrast, tests for somatic disease do not raise any new or controversial ethical issues and might reasonably be considered in the same light as any other diagnostic tool.

2.33 It is likely that tests for predisposition to multifactorial disorders will eventually become available although it may be a long way into the future before these become a reality. These tests will not be indicative of either presymptomatic illness or of any inevitability that the disease will ever occur. They will, however, give warning of a greater than normal degree of risk. In a sense, they are analogous to other known risk factors such as blood pressure, cholesterol level etc. and, in much the same way, knowledge of these predispositions will offer individuals the opportunity to adapt their lifestyle and to minimise the risk.

2.34 It will be apparent that genetic disease is not just a limited subset of the human condition. It is now recognised that many more conditions, than was once thought to have been the case, have a genetic component and, indeed, that most non-hereditary diseases can also be traced to a genetic mutation. A huge international effort is being directed at the mapping of the human genetic code – an effort which is producing new genetic tests at a bewildering rate. It seems likely that, over time, genetic technology will emerge as a routine tool at the forefront of many, if not most, facets of medical practice.

3. The Political Framework

3.1 Recognition of the extreme sensitivity of the information potentially revealed by genetic testing is leading to intense international debate in legal, political and ethical circles about the use of, and access to, genetic information.

3.2 Naturally, the issues raised extend far beyond the boundaries of direct concern to our profession but, in this section we limit commentary to those areas of the debate which have relevance to insurance.

3.3 As far back as 1989, the European Parliament adopted a resolution on the Ethical and Legal Problems of Genetic Engineering. Principle 19 of that resolution bans insurance companies from demanding a genetic test or from being informed of the result of a test which had already been carried out. Principle 20 states that an insurer has no right to be notified of all of the genetic data known to the policyholder. This resolution has no legal force in the member states. In contrast to a Directive, which demands adherence, such a resolution only encourages action.

3.4 Whilst a number of jurisdictions, both within Europe and elsewhere, have reached for the statute book, the UK Government has taken a more measured approach in the search for practical resolution of conflicting interests in the genetic debate.

3.5 One of the principal contributions to the debate in the UK has been a report produced in 1993 by the Nuffield Council of Bioethics and entitled, *Genetic Screening - Ethical Issues*. Chapter 7 of this report contains a very clear and balanced view of the issues that relate to insurance. Its recommendations can be summarised as follows:

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- That British insurance companies should adhere to their practice of not requiring genetic tests as a prerequisite of insurance cover
- That there should be discussions between Government and the insurance industry about the future use of genetic data.
- That, pending the outcome of those discussions, insurance companies should grant a temporary moratorium on the requirement for disclosure of genetic data. However, there were two important qualifications to this recommendation. Firstly, that, in the case of individuals with a known family history of genetic disease, those individuals may be asked to disclose the result of any relevant genetic tests. Secondly, that the moratorium should only apply to policies of 'moderate size' – it being left to discussion between the industry and the Government as to what that limit should be.

3.6 The House of Commons Select Committee on Science and Technology published a report on *"Human Genetics, The Science and its Consequences"* in July 1995. Whilst the full report concerns itself with a very much wider range of issues, it contains a significant section which addresses the insurance implications of genetics. In forming its opinions, the Committee had taken evidence from, amongst others, a delegation from the Association of British Insurers.

3.7 The report acknowledges that an individual with an unfavourable test result has an incentive to take out life insurance and recognises that current practice of insurers in seeking disclosure of test results is to avoid such adverse selection.

3.8 The Committee accepted that the insurance industry has, collectively, tried to deal with genetics in a responsible way but, nonetheless, registered a number of concerns:

- The Committee expressed the view that the industry had reacted with "undue complacency" in preparing for the potentially profound effects that the development of genetic science could have in the relatively short term. It recommended that the industry be given a year in which "to propose a solution acceptable to Parliament" with the threat of legislation should it fail to do so.

- that insurance implications would deter people from taking genetic tests and, by so doing, hinder research;

- that there were doubts about insurance companies abilities to interpret the results of tests, particularly in the early stages of development of genetic tests when their implications are unclear or unproven;

- that, if one insurance company attempted to "cherry pick" by offering preferential rates to those with good genetic profiles, others would be forced to do so.

3.9 The Government of the day did not entirely accept these recommendations and, in its response, expressed the view that legislation would not be appropriate now or in the foreseeable future. Nor did it agree to the imposition of a deadline for the development of a solution to the use of genetic information. However, the Government encouraged the industry to enter into dialogue with geneticists with a view to the development of an industry-wide code of practice and hoped "to see substantial progress within 12 months".

3.10 The industry's response took a little longer than 12 months to emerge and when it came, in February 1997, was in the form of an ABI Policy Statement. The essence of this Statement was that for a two-year period:

- the ABI reaffirmed that its members would not require applicants to undergo genetic testing on application for life insurance;
- no account would be taken of the results of genetic tests, which may have been taken for other purposes, in the underwriting of new life insurance policies of sums assured up to a total of £100,000 which are directly linked to a new mortgage.
- Notwithstanding the previous undertaking, applicants would be expected to disclose the results of any earlier genetic test.
- Individual companies were left with the freedom to decide whether or not they wished to extend the concession to other types of policies.

3.11 There is little doubt that the impact of the ABI Statement was diminished by the delay in its emergence and the thin veneer of unanimity amongst the membership.

3.12 Nevertheless, the spectre of legislative interference in insurance affairs has, so far, been somewhat remote although the high profile of the genetics issue could mean that immunity from legislation could prove to be a fragile thing. Political opinion has an understandable tendency to respond to public pressure. As Theodore Roosevelt, who presumably knew about these things, was once heard to observe; "The successful politician is he who says what everybody is thinking most often and in the loudest voice." Given that we have had a change of government it is not beyond the bounds of possibility that the temperature of the political debate could be raised.

3.13 The next catalyst could prove to be a report from the Insurance Group of the Human Genetics Advisory Commission. The Human Genetics

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Advisory Commission was established as an independent group to advise both Industry and Health Ministries on developments in human genetics. The Insurance Group has been consulting with experts from within and without the insurance industry and is expected to publish its findings towards the end of 1997.

3.14 Political pressure could yet come in the form of European legislation. In February 1992, The Committee of Ministers of the Council of Europe adopted the Recommendation on Genetic Testing and Screening for Health Care Purposes. Principle 7 of this recommendation prohibits insurance companies from requiring genetic tests, or from enquiring about results of previously performed tests, as a pre-condition of an insurance policy.

3.15 Belgium was the first country to incorporate this recommendation into law. Interestingly, the prohibition is upon the *transmission* of data rather than the use of data. As a result, the onus is upon the applicant to refrain from declaring genetic data, even if it would be to his or her advantage to do so.

3.16 The Committee of Ministers has recently adopted the final version of the Convention on Human Rights and Biomedicine. The convention is now open for signature and any member state which ratifies this convention will be required to adopt its provisions into national law. Article 11 of the convention states: *"Any form of discrimination against a person on the grounds of his or her genetic heritage is prohibited."*

3.17 Insurance, by its very nature, is discriminatory. It is therefore expected that, in due course, an explanatory report will be produced which, amongst other things, will explain the intended meaning of the word "discrimination". The supplementary report could possibly exempt insurance altogether or permit classification which is equitable or based upon reliable statistical data.

3.18 Article 12 goes on to say:
" Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate counselling."

3.19 France, Austria, Norway and the Netherlands are all countries which have adopted, either voluntarily or as a result of legislative action, bans upon the use of genetic tests for insurance purposes.

3.20 France adopted a law in 1994 which limited the use of genetic tests to medical purposes or scientific research. Concurrently, the French Federation of Insurance Companies announced a 5-year voluntary ban on the use of genetic information in the assessment of insurability.

3.21 In Austria, legislation bans the use of genetic tests by employers or insurers.

3.22 A law introduced in Norway in 1994 restricted the use of genetic tests to medical diagnostic and/or therapeutic purposes. It also prevents anyone from enquiring whether a genetic test has been performed other than where symptoms are present.

3.23 The Netherlands first introduced a 5-year moratorium in 1990. This has recently been extended indefinitely subject to a new provision that it can be cancelled with a 2-year notice period. Under this moratorium, insurers have agreed to abstain from seeking genetic tests and from using genetic information in the assessment of policies below NLG300,000 (approximately £100,000).

4. Insurance Issues

4.1 There is a common perception that the science of genetic testing will present the insurance industry with a powerful tool which will be used to identify those with a favourable genetic profile. These fears may have been fuelled by moves in some markets - particularly in the United States -towards 'preferred underwriting' approaches through which some companies have sought to segment the insured population into smaller, more tightly homogeneous units.

4.2 To some, the issue is quite fundamental. For them there is a firm belief that it is intrinsically wrong for insurers (or indeed others) to discriminate against those who have a genetic abnormality.

4.3 These concerns raise questions about the role which insurance should play in our society and the extent to which a private insurance industry can or should be a vehicle for the expression of public policy. In this section we examine the issue of access to insurance in the context of a voluntary private insurance sector. This is a discussion which has wider relevance but the debate will focus on the implications which are raised by the prospect of the increasing use of genetic testing in clinical practice.

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The franchise to insurance

4.4 Professor Wilkie (1996) recounts the history of the way in which risk classification practices have emerged. The current reality is that life insurance is accessible to a vast majority of the population. Claims are often made that 95% of life insurance applicants are accepted on 'ordinary terms'. However, the logic of this statement, although well understood by those in the industry, may not convey an entirely accurate impression to others. 'Ordinary terms' does not mean the same terms for all 95%; nor even the same terms for people of a similar age. It is more likely to imply terms which are standard for the age, sex and smoking status of the insured.

4.5 Furthermore, this does not imply that 95% of the population will enjoy insurance cover on normal terms since the very existence of a selection procedure means that some people in poor health will be discouraged from applying.

4.6 There seems little reason to suppose that the proportion of the population that will be accepted for insurance will suffer as a result of genetic advances. History has demonstrated that advances in medical knowledge have consistently contributed to improvements in longevity and a broadening of access to life insurance. The development of genetic science will not, of itself, arrest this trend. It is more likely that a better understanding of the interaction between genetic makeup and environmental influences will, over time, improve the effectiveness of health management and, as a result, lead to further improvements in mortality. This being so, there is a clear coincidence of interest between life insurance providers and society as a whole in the successful development of genetic technology.

4.7 Equally, it would be unduly alarmist to suggest that improvements in the ability to detect disease would result in the emergence of an 'insurance underclass'. Generally advances in diagnosis have led to better treatment and improved understanding of the risk factors. As a result, individuals who might previously have been declined or severely rated are more likely to be accepted into the insurance pool. Historically this has been the case - for example in the underwriting of diabetes and of applicants with raised blood pressure.

4.8 However, advancements in the diagnosis of life threatening conditions do not always go hand-in-hand with improvements in the timeliness or quality of treatment. That is not to say that such advances have no value. Their justification may be found in their epidemiological role if not in their clinical value to the individual. But, where the development of diagnostic techniques precedes advances in treatment, there is a danger that the newly acquired knowledge may affect the terms on which insurance is available. This may be so even where the individual is showing no physical signs of disease.

4.9 One may draw examples from the tests for monogenic disorders. Such tests will be justified, even in the absence of parallel improvements in treatment, because of the implications for family planning. The same was also true of testing for HIV infection. Before multi-drug thereapies became available, the result did not change the outcome for the individual but the process of testing was clearly in the wider public interest.

Genetic profile as an underwriting tool?

4.10 The link between genetic profile and prediction of disease is by no means straight forward - even with many of the monogenic disorders. It remains a fact that we know little of the all-important interaction between multifactorial genetic defects - defects which might affect more than one gene - and other behavioural and environmental factors. As a result, it may be sometime before specialists in the field of genetics can predict the impact of specific genetic defects on longevity with confidence.

4.11 The equivocal value of the knowledge that might be gained means that, as yet, genetic testing appears to have little value as a tool of the life insurance underwriter. Other tests for predisposition to many of the common disorders are more readily available and better understood - blood tests, urinalyses, blood pressure readings etc. Even if that were not the case, it would be wise to heed the words of The Rt. Hon Lord Griffith (1992) "Unless there is any compelling necessity associated with the very preservation of society, I do not think that any pressure should be put upon any person to submit to a genetic test".

Disclosure of information

4.12 However, one must draw a distinction between the active use of genetic tests as a routine underwriting tool and the more passive requirement for disclosure of the results of tests which have been conducted for other purposes. It is the question, whether or not applicants should be absolved of any requirement to disclose the results of any such test, which poses the more pressing debate.

4.13 The concept that individuals might, with legislative sanction, withhold information which they know or suspect to be material to their risk raises interesting philosophical issues. The inherent inequality of information between insured and insurer about the nature of the risk being run meant that insurance developed as a contract of *utmost good faith* with an obligation on each party to disclose relevant information. As pointed out by Wilkie the principles of utmost good faith have been amended to put an onus on the insurer to give guidance to the applicant on what constitutes material information. Nevertheless, explicit, or even tacit, recognition of the right to

withhold information would strike at one of the core principles upon which private insurance is based.

4.14 Lord Griffith is unequivocal about the legal position; "If an applicant for insurance has undergone a genetic test which reveals that he suffers a hereditary disorder threatening his health he must disclose it to the insurance company for it manifestly affects the risk he wishes to insure against."

4.15 Dr O'Neill (1996) argues that, notwithstanding the legal position, it is wrong, in principle, to 'discriminate' against those who are found to have a genetic abnormality. The arguments are predicated on the principle that individuals should have the right of access to life insurance if the causes of their increased risk are not of their making. In so far as none of has control over our genetic make-up it is clearly the case that no fault can be ascribed to those who have a 'genetic disease'. But, it is also the case that, with the exception of willing exposure to known risks, such as smoking, no one can be held responsible for the causes of his own mortality.

4.16 Arguments are also put forward that the need to disclose information about genetic tests to insurers will discourage individuals from taking tests and inhibit the development of the science. However, it is difficult to untangle the extent to which these fears are unprompted or to which they are a consequence of the counselling given. Those who argue the deterrent factor might say the same of a range of other diagnostic tests which *could* have an impact on insurability. It is possible that the concerns about disclosure of genetic test results is a matter of unfamiliarity and lack of confidence in the insurers ability to understand their significance. Perhaps the same may have been said of other tests, such as blood pressure tests; ECGs; blood tests etc, in the early years of their use. There is no suggestion that the need to disclose the results of such tests now has a deleterious effect upon their use in clinical medicine.

Questions of access and equity

4.17 Wilkie draws a distinction between *mutuality*, where individuals contribute to the pool through a premium which relates to the risk they bring, and *solidarity* where the correlation between premium and risk no longer applies. In this case, premiums may be equal, regardless of risk, or assessed according to ability to pay.

4.18 The foundations of private insurance are rooted firmly in the pooling of risks but, at the same time, underpinned by attempts to achieve broad equity, in terms of equivalence of value, between cost and benefit. To this extent, life insurance takes on the characteristics of mutuality

4.19 To support this system, insurers adopt the concept of risk classification through which individuals are categorised in broadly homogeneous groups. In motor and personal lines property insurances, the subdivision of risks has been refined to take an increasing range of factors into account. In life assurance, by contrast, the vast majority of risks are now classified by the three factors of age, sex and smoking status. For the remainder, some further adjustment in premiums may be required to reflect additional risks posed by health, occupation or leisure pursuits.

4.20 It is accepted that the 'equality of value' is by no means perfect and to that extent there are some concessions to 'solidarity'. The 'ordinary rates' group may encompass some quite wide variations in expected mortality. Nevertheless, the aim is to limit overt cross-subsidy between individuals presenting significantly different risk profiles. Discrimination *between* - as opposed to *against* - applicants is part and parcel of the risk evaluation process. Let us draw once again upon the wisdom of Lord Griffith: "The essential skill of an insurer is the assessment of risk to the insured. It will defeat the social purpose of insurance if this risk cannot be reasonably accurately assessed."

4.21 Dr O'Neill sees it differently. She argues that whilst the process of risk classification can be justified in the case of motor insurance the same arguments do not apply to life insurance. She points out that, in motor insurance, the individual can exercise control over the risk factors and, furthermore, that it is socially acceptable for bad drivers to be penalised (cf 4.15).

4.22 As one moves to extremes of segmentation, the principles of risk pooling and those of equality of value become somewhat at odds. The more refined risk classification becomes, the more limited will be the opportunities to spread risk.

4.23 It is open to debate whether, in fact, a detailed segmentation of risk, whether through the use of genetic information or otherwise, is in the interests of the industry as a whole. An individual insurer may gain some 'first mover' advantage through a more refined risk classification process which allows it to compete more effectively for the better risks. However, any significant success is likely to force an early competitive response which will make that initial advantage short lived.

4.24 In the process the industry may turn its back on a significant area of opportunity. With pressures upon the public purse there is an opportunity for the industry to present itself as a custodian of private welfare provision. Such ambitions are unlikely to be realised if 'cherry picking' - and in particular,

'cherry picking' on the basis of genetic information - is seen to be the norm for the industry.

4.25 It is by no means axiomatic that a system of insurance must necessarily be based upon assumptions of equality of value. The *aggregation* of risks is consistent with the principles of risk pooling although, the greater the heterogeneity of risks, the further one moves towards to the principles of solidarity. A system which grants equality of access can work satisfactorily in circumstances where there is compulsion to participate. The system can also operate where there is consensus amongst the insureds that the cross-subsidy is reasonable or where there is ignorance of the level of cross-subsidy involved. The crucial issue is that those who are, in effect, funding the subsidy should remain motivated to join the insurance pool.

4.26 Dr Robert Pokorski (1997) observes that an insurance company could insure every one who passed by a designated point so long as the practice did not become public knowledge. It is the fact that purchasing decisions are not entirely random that makes some form of screening a necessity.

4.27 The Friendly Society movement thrived without strict adherence to principles of solidarity. However, the community of interests which underpinned their existence finds less ready acceptance amongst a generation that has grown up with the Welfare State and become unused to the concept of mutual self-help as a means to provide a safety net.

4.28 Whilst the status quo is by no means the only possible model on which insurance principles can be built, it is difficult to see how equality of access can sit comfortably with a system of insurance which is both private and voluntary. Automatic rights of access would inevitably bring changes in buying behaviour, both in the timing of purchase and the amount of insurance bought. These would have a fundamental impact upon insurance costs - involving increases for which the only source of funding would be other policyholders. The magnitude of the cross-subsidy required would lead to a spiralling of costs as those in poor health would have a greater propensity to buy life insurance protection whilst healthy lives would have little incentive to remain in the insurance pool. Indeed there would be little incentive for anyone to buy full life insurance protection until the first symptoms of malaise are felt. Up to that point accident cover would suffice.

4.29 Thus it would seem that a voluntary system can only coexist with universality of rights of access if the cross-subsidies are funded from a source outside of the insured population. Even governments might balk at underwriting such an open-ended commitment.

Genetic disadvantage - a case for special treatment?

4.30 However, in the context of this paper, our concern is not merely with the merits or problems of universality of access but whether a voluntary system of insurance can operate equitably without access to genetic information. The fact remains that that the present level of knowledge is such that there are only a very limited number of genetic disorders which, in the absence of other risk factors, would warrant denial of insurance or substantial rating. But, is there a case for a guarantee of special treatment?

4.31 As we shall demonstrate in the next section, it may be possible to grant *limited* rights of access to the group of asymptomatic adults who suffer from certain of the genetic disorders. Their numbers are sufficiently small in comparison to the broader policyholder base that the effect of the cross-subsidy will not be apparent or too unpalatable. However, there must be doubt whether, in a private system of insurance, it would be equitable or sustainable to guarantee access to insurance to the 'genetically' disadvantaged whilst denying a similar privilege to those suffering from a clinically diagnosed condition. Some argue that there is difference in that the former group are asymptomatic and merely have a predisposition to disease whilst the latter group may be exhibiting real signs of illness. However, it remains the case that each might have a similar predisposition to claim and it is this that is the critical criterion. Would it be right or logical, for example, to guarantee insurance to an asymptomatic 40 year old with the Huntington gene whilst denying the same cover to someone of a similar age with HIV or a history of heart disease?

4.32 Furthermore, there seems little justification in equity if access to insurance depends upon having a politically acceptable form of disadvantage. There is another group of 'disadvantaged' who also have need to make provision for their dependants and who may find themselves excluded from the insured population. These are the economically disadvantaged - those who cannot afford the premiums. It may well be the case that someone with a genetic disadvantage may be better able to pay an 'actuarially appropriate' premium than someone of lesser means. Yet, clearly, the economically disadvantaged can only be brought within the insurance net in a system based on the principles of solidarity.

Questions of definition

4.33 The granting of special treatment on the grounds of genetic disadvantage has a further and perhaps more fundamental difficulty which relates to the matter of definition. The perception of genetic disease is generally one of disease acquired through inherited genes. It is now recognised that many more conditions than was once thought to be the case have a genetic component. Furthermore, it has come to light that most non-hereditary diseases are also linked to genetic mutations. In the case of the

acquired diseases, only a limited number of cells may be affected but, nonetheless, the cause may reasonably be described as being 'genetic'. What is of particular concern is the likelihood that genetic testing techniques will be used increasingly in their diagnosis.

4.34 As we have seen, there are undoubtedly those who would seek, not only to ban insurers from seeking genetic tests, but also to bar their access to results of tests that have been conducted for other purposes. It is clear that the protagonists of the case, either for or against legislation or codes of practice, need to have a very clear understanding of what is included in their interpretation of a genetic test. Unless great care is exercised, any such barriers could have consequences of much greater significance than was intended. This will be particularly true if, as seems likely, genetic testing assumes an increasing role in diagnostic medicine. It would be a pyrrhic victory indeed if protection intended for the few were to make access to insurance more difficult or less affordable for all.

5. Towards a Practical Response

5.1 In the previous section we discussed some philosophical issues relating to the rights of access to insurance which would be raised by the increasing availability of genetic tests. However, the concerns about the implications of insurance for the development of genetic testing are not limited to calls for rights of access but will also include:

- fears amongst health professionals that the need to disclose genetic testing information in insurance applications will discourage the development of genetic testing.

- concerns about the confidentiality of genetic information.

- concerns about the ability of industry practitioners to interpret genetic test results

5.2 The insurance industry has its own concerns which have contributed to the apparent difficulty the industry has had in finding common ground with its critics. These concerns are:

- concessions made now could become precedents, in a field which is changing rapidly, before the full implications can be properly evaluated.

- pressure will be exerted to extend any concessions beyond the strict confines of life insurance and into critical illness and other forms of disability or health coverages.

- a backlash from other interest groups who might argue equal rights to such a concession.

5.3 What practical steps might be taken to mitigate some of the public concerns without causing material damage to the integrity of the selection process or to the prudent operation of a sound insurance industry? Pokorski (1997) has argued strongly that what is at stake is not just a question of extra costs being small or large, tolerable or intolerable; it is the very scientific principle of voluntary insurance. However, it could be argued that if extra costs are regarded as containable, the purity of the principle will not be allowed to over-ride social concerns; it might therefore be unfortunate if matters were pushed to a conclusion in the context of life insurance alone. In this context, the lack of quantitative work, especially in the areas of health and long term care insurance, should be of concern.

5.4 There is consensus within the industry that insurers should not initiate the use of genetic tests as a means of screening proposers. It is likely that unanimity on this issue will ensue unless:

- over-the-counter tests become freely available which makes the industry open to non-disclosure or,

- a substantial new entrant was to come to the market with the intention of 'cherry-picking' on the basis of genetic screening.

5.5 In either case insurers might feel compelled to respond to protect their positions.

5.6 One should not lose sight of the fact that, other things being equal - buying behaviour, access to traditional forms of medical and financial evidence - genetic science does not, of itself, increase the risk. The risk is of anti-selection - the risk that, human nature being what it is, buying behaviour will be influenced by the knowledge that genetic testing can bring.

5.7 The greater challenge is to find ways in which the need for disclosure of tests, performed for other purposes, might be limited. Various solutions have been proposed, but in the absence of much quantitative work, these run the risk of only leading to confrontations between different sets of principles.

5.8 At one extreme, some would argue that private insurers should not have to give way; they operate on the basis of mutuality and it would be a fundamental error (indeed, a scientific error) to make them relinquish that principle. Pokorski (1997) is one who defends the supremacy of the scientific

principle of insurance, and the apparatus that comes with it. This is, of course, quite different from saying that private insurers could not operate on the basis of solidarity within a different framework, such as compulsory insurance.

5.9 At the other extreme, some would argue that principles of justice are supreme, and should be upheld over principles which tend to favour the interests of corporations, even such scientific principles as those that underpin insurance. See Moultrie & Thomas (1996) for a clear example of such a view, or Barr (1996) for some suggested consequences for the conduct of insurance business. These principles weigh most heavily in the provision of services which might be regarded as basic to a decent life; health care, disability income and long term care.

5.10 In the middle are those who are pulled in both directions. It is hard to argue with principles based on a strong sense of justice, but it is also hard to argue with science. To these individuals, the question is a more pragmatic one, of where to draw the line. The application of the principles of insurance, in practice, is far from exact; there is therefore little to be gained, and much that might be lost, by mounting a ferocious defence of (for example) the "right to underwrite" unless there is a clear risk of an intolerable outcome. If it is likely that the costs of some departure from the pure scientific principle are modest, then the question becomes that of seeking practical means to meet, and to allocate, these costs; for example, by various forms of retrospective pricing. Barr recognised that, if concessions are to made to those who would otherwise be subject to rating or declinature, the cost must be borne by others, for example:

- by spreading the cost amongst the policyholders of the insurance company concerned
- by pooling risk across the policyholders of all insurance companies
- by placing the cost burden on taxpayers generally
- by the individual bearing part of the additional cost with the remainder being spread in one of the above three ways.

5.11 The extent to which any of these provides a workable solution will depend upon the safeguards that can be built in to limit the quantum of the subsidy required - which, viewed from the opposite perspective, will limit the value of the concession. But, there must come a point at which departures from the scientific principle are so significant that a stand ought to be made (recall that in 1897, the State of Indiana tried to incorporate into law some mathematical constructions which yielded a value of pi of 9.2376! (Beckman, 1971)). One danger of the pragmatic approach is that it could lead to a slippery slope; once a principle has been conceded where there is relatively

little risk, it might fail as a defence where there is much more risk (Pokorski, 1997). The countervailing danger is that insurers' natural desires to remain in business lead them to disprove their own warnings of dire consequences, with obvious effect on their credibility.

5.12 At present, some UK life insurers have announced that they do not think that genetic testing will have a significant impact on life insurance and have eschewed any use of genetic tests. Some quantitative work, described later, tends to the same conclusion. No health or long term care insurers, as yet, have followed suit, and it is unlikely that any will. Also, moratoria have been adopted by life insurers in several countries, mostly depending on some maximum benefit. The pragmatist's line, therefore, seems to be drawn somewhere between life insurance and other forms of insurance.

5.13 In the UK, legislators and others have acknowledged the principle of private, mutual insurance, and have accepted that adverse selection is a real concern. There is, however, very little evidence of how much it would cost life insurers, and even less evidence of the cost to health and long term care insurers, so it is unclear how heavily this will weigh in the scales, under pressure to shift welfare costs. The same lack of evidence makes it difficult to assess the practicality of any of the suggested means of controlling or spreading any subsidies, and so does little to foster a meeting of minds.

5.14 Macdonald (1997), in a paper to a joint meeting of the Royal Society and the actuarial profession in the UK, developed a Markov model to illustrate the possible impact of adverse selection on life insurance. In all cases studied, the most significant impact on costs is where those anti-selecting effect policies with higher than average sums assured. For example, this factor proved to be of greater significance than the propensity to anti-select.

5.15 Macdonald acknowledges that his results are based on highly uncertain parameters and must therefore be taken as being illustrative of relativities and rough orders of magnitude rather than as an absolute statement of costs of anti-selection. However, a model of severe late-onset monogenic disorders suggest that, even with very high levels of adverse selection, the cost of including such lives in the insurance pool would be equivalent to an increase to the standard premium of between 10 and 30%, provided that the amount of insurance coverage granted is no greater than the average.

5.16 His results confirm, what may be deduced from general reasoning, that the closer the 'adverse selector' is to the likely age of onset of disease, the greater is the cost. He therefore questions whether it would be fair for

someone who obtained genetic information at the age of 20 to defer a 'right to insure' until say, the age of 40.

5.17 Normal rules of elasticity of demand suggest that an increase in price will bring about a reduction in demand which, in practice, is likely to affect the number of healthy lives seeking insurance. This is a variable which is not built in to the model. However, if one takes the view that demand for term cover is relatively inelastic over the range hypothesised by Macdonald, this factor can be ignored.

5.18 At first sight an increase of the order 10% might appear to be a manageable and reasonable price to be paid by the many to deliver a measure of financial security to the few who might otherwise have difficulty in obtaining insurance. However, one must remember that those susceptible to late-onset monogenic disorders are a limited subset of those with some form of genetic abnormality and certainly very limited subset of the total population that might have difficulty in obtaining insurance. The cost of cross-subsidy would escalate if concessions to prudent rules of underwriting evidence were available to a wider population.

5.19 It is important to remember that Macdonald was modelling the impact of adverse selection upon life insurance. The knowledge which an individual might gain regarding his or her susceptibility to specific diseases means that the results of genetic tests would be indispensable to insurers of critical illness policies and of certain other health products.

5.20 The Association of British Insurers has been the focal point for the genetics debate by the life insurance companies over the last two years. Professor Sandy Raeburn, a leading geneticist was appointed the ABI's Genetic Adviser in October 1996. The key development was a position paper 'Developments in Genetic Science and the Insurance Industry' circulated in January 1997.

5.21 This paper proposed three options:

- Option 1 involved no concession but instead reaffirmed the policy of the industry not to require individuals to take genetic tests as a condition for insurance. Any genetic tests already taken were to be disclosed on any application for insurance.

- Option 2 contained a limited concession, insurers would not use the results of genetic tests already undertaken if the insurance was linked to a mortgage and the sum insured was limited to £75,000.

- Option 3 was a broader concession; insurers would not take account of the results of any genetic test in deciding the terms and conditions of insurance provided the proposer was not seeking unreasonable levels of life insurance in relation to his or her circumstances.

5.22 All three options would still require the full disclosure of genetic test results but options 2 and 3 would disregard the results. The rationale for this was three fold. First, it up held the principle of 'utmost good faith'. Second, it would enable the collation of information on proposals where genetic test results are given. This data could give an indication of the cost to the industry of any concession agreed. Third, it avoids the difficulty of explaining what does and what does not have to be disclosed.

5.23 Such an approach would leave unanswered concerns regarding the confidentiality of genetic information. There may also be room for dispute where the genetic test result confirms information gained from normal clinical evidence. In these circumstances, it may be difficult to satisfy the applicant that the results of his genetic test have been ignored.

5.24 Considering option 2 in more detail, what are the merits of this approach?

5.25 It avoids the major risk from adverse selection by linking the concession to both the presence and the quantum of the mortgage.

5.26 An asymptomatic individual with a positive test is unlikely to take out a significantly higher mortgage than he would otherwise had done - particularly as mortgages will be limited by income.

6. Summary and Conclusion

6.1 Genetic science is driven by the prospect of advances in knowledge and medical care, both positive forces. Unfortunately, insurance is widely seen as an impediment, holding back applications because of fears about the consequences for a `genetic underclass'. It is important that the actuarial profession, the insurance industry and other interested parties reach methods of dealing with genetic information that are practical and acceptable to all parties.

6.2 First, insurers must understand the implications of genetic disorders. There range from monogenic inherited disorders with very specific outcomes (such as Huntington's disease) or with variable outcomes (such cystic fibrosis) through polygenic disorders which represent one of many

influences on the outcome, to non-inherited somatic disorders (such as lead to many cancers).

6.3 Striking a balance between workable insurance practice, in which adverse selection is controlled, and acceptable public policy, in which discrimination is not extended unreasonably, will not be easy. At one extreme is the view that the scientific principle of insurance should be upheld, if the purchase of insurance is in any way voluntary. At the other is the view that insurance principles cannot override natural justice. A pragmatist might acknowledge the strengths of both arguments, and ask how much any departure from the unfettered `right to underwrite' might cost. Little information is available to help, as yet. One study, confined to life assurance, suggests that the costs would not be large provided some limits were placed on the sums assured that could be obtained under limited underwriting. No comparable studies have been carried out for health or long term care insurance, where greater problems might be expected.

6.4 More research is needed urgently into all aspects of insurance-buying behaviour and adverse selection, as well as the implications of the purely statistical knowledge to be gained from genetic tests. Such research will not be easy, and might require the insurance industry to look beyond the statistics it gathers in the ordinary course of its business, but, in its absence, policy-makers are likely to be more strongly swayed in directions which appear to be supported by relevant research.

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