ABSTRACT OF THE DISCUSSION

HELD BY THE INSTITUTE OF ACTUARIES

Ms D. A. Akers, F.I.A. (introducing the paper)**:** The authors of this paper are members of the Genetics Group of the Social Policy Board, whose main aim is to inform the debate on genetics issues where actuarial input is relevant. It is about six years since the subject of genetics and insurance last had a formal actuarial airing, with written papers on the subject. Much ground has been covered since then with a number of reports from various bodies, such as the Human Genetics Commission and the House of Commons Science and Technology Select Committee. This paper brings the subject up to date and looks, at times speculatively, to the future. Some of the underlying philosophical issues are covered, such as solidarity versus mutuality as a basis for insurance, and whether risk classification constitutes fair or unfair discrimination, and the concept of that emotive term 'the genetic underclass'.

Much important actuarial research has been undertaken in recent years in the academic environment of Heriot-Watt University into the potential effects of adverse selection and other insurance issues. However, the actuarial work required for the approval of test results for insurances was carried out differently, over a shorter time frame, by practising insurance actuaries with a more pragmatic approach. This was not without criticism. How should the profession address the requirements of society for ever greater transparency and the need for the industry to provide evidence for the decisions that affect individuals when taking out insurance? Currently, we have a moratorium on the use in underwriting of virtually all adverse genetic test results. What should happen after that expires in 2006? Will insurers be able to put forward reasoning adequate to justify any change, or is the ban likely to become permanent, as in some other countries? Should the requirement be for the industry to prove vulnerability to the aggregate effect of the ban, rather than to demonstrate the justification for using results in underwriting at the level of individual policies? Will the broader principle of the freedom to underwrite be defended adequately for the future? Will the current uncertainty as to the pace of relevant developments in genetics, and their impact on insurance, become a real and serious threat? Can ideology and operability be reconciled?

Mr R. H. Plumb, F.I.A. (opening the discussion)**:** I have to declare that, in addition to being a Fellow of this Institute, I inherited a malign genetic condition from my father. It was quite clearly from my father; he had suffered from it before me. For the first 20 years of my life I lived with the knowledge that I would need a life-saving operation when the medical problem arose, the alternative would be dying in agony three years later. I had the operation at the age of 20, with a successful recovery. Consequently, I am very aware of some of the problems arising from having the so-called wrong genetic inheritance.

The paper outlines the work which has been undertaken by members of the actuarial profession and others, of the impact of genetics on underwriting and policy design issues in life and health insurance. Section 1 outlines a summary of the history of this subject in the United Kingdom, with particular reference to the legal submissions made to the various bodies set up by Parliament to oversee this issue. These bodies were created to resolve some of the genuine concerns surrounding the effect of genetics on life and health insurance.

Section 2 reviews the problems arising from the use of solidarity and equality as required by the consumer, and implicitly required in the U.K. by the Government, and that of mutuality, with each risk bearing the rate for the risk, that is no undue cross-subsidies. There are real concerns that our insurance industry, with its international outlook, should not be asked to restrict itself only to insuring modest amounts for the bulk of the population, thereby ignoring the requirements, in some cases, for high sums insured for high benefits.

The actuarial profession has been able to use the techniques of multi-state modelling, as

described in Section 3. This technique has proved to be a very good method of exploring the additional risks faced by an insurer in relaxing acceptance criteria for the specific genetic condition under study. The technique relies upon good estimates being available of the prevalence of the genetic condition within the general population.

It is a matter of considerable concern to me that, despite the enormous amount of money being spent on medical research around the world, so little of the findings can be used as source data for further mathematical and statistical research. Paragraphs 3.4.4 and 3.4.5 outline the problems in this area. While actuaries are used to assembling data from a variety of sources, it is disappointing to find that so much of the medical research results are completely unusable. It would be of considerable value to everyone, including the consumers, if efforts could be made to improve the quality of medical data available for publication. In addition to estimating the risks based on current knowledge, the modelling provides a platform for future comparison as additional information becomes available.

The research to-date has shown that there have been very few instances of genetics having a profound impact on the underwriting acceptance of a risk by an insurance company. The major exception to-date has been Huntington's disease, which is a very nasty disease. Actuarial research into this condition has shed light on the circumstances, where acceptance terms can now be granted with the increase in knowledge now available.

The insurance industry's response to the Genetics and Insurance Committee, as outlined in Section 4, has shown that a rigorous approach is necessary. The initial submissions had no precedents on which to build, and detailed consideration will need to be given to the mechanics of this process, as and when it is continued.

However, discrimination and underwriting are two different perspectives on the same insurance acceptance procedure. Insurance companies do need to limit their vulnerability to mortality and morbidity losses, as mentioned in ¶5.6.2. The public have been educated by the media in the past few months on the vulnerability of insurance companies, as a result of the decline in the stock market, with its consequent impact on the level of solvency margins.

We are fortunate in this country to have a National Health Service giving universal access to healthcare. This means that our private medical expense insurance contracts do not have to grapple with the problems faced elsewhere on the genetic impacts on a contract giving unrestricted cover for acute and chronic medical conditions. Reference is made in ¶1.9 to this type of insurance available in the United States of America. I am given to understand that the contracts there are largely written on a group basis, with most benefits being on a defined benefit basis. Therefore, the ban on the use of genetic test results has little or no impact. It will be very interesting to monitor the impact of this ban on the U.S. PMI insurance mechanisms if the switch to defined contribution continues, as is happening in the U.S.A., where some employees may be obliged to purchase their insurance on an individual basis.

Can we ignore the area of genetics because little of note has been found? Currently, there are rapid advances in medical research into genetics. For example, in the last few days announcements have been made that hypertension has a genetic marker and that leprosy also has a genetic component.

It seems that, in this country, we may concentrate on the overall health improvements in the population as proxies for the underlying genetic indicators. At my church the Ten Commandments are inscribed on the altar wall. Are we going to see the Health Commandments hang on a tapestry here at some point in the future? The Health Commandments would obviously start with:

— 'Thou shalt not smoke'; and continue with:
— 'Thou shalt eat five portions of fresh fruit and vegetables each day'; or in my case:
— 'Thou shalt not eat more than five portions of fruit and vegetables each day'. (In other words, obesity is now becoming a social discriminator.)

There are many other commandments to add to the list.

Our problem is that nobody really knows what lies ahead. We have a system on genetics which is currently working. On the one hand, we have an element of control in a formal mechanism, which has been created to scrutinise and approve genetic tests and procedures for insurance. On the other hand, the insurance industry is able to offer insurances for all and on a fully underwritten basis for very large sums insured or benefits.

Mr I. J. Kenna, A.I.A.: It is clear that there is a correspondence between an individual's genetic make-up and his tendency to various innate disorders. Having a tendency to an innate disorder, such as cancer, does not mean that one is doomed to get cancer. One can make the necessary lifestyle or dietary changes referred to in ¶2.4.3. Most people will not be willing to make the rather drastic dietary changes which will protect them from all innate disorders. Therefore, we need to look more deeply.

There are two main attitudes to the problems of bodily make-up and inheritance. The Mendelian school regards the body as merely an environment for the gene. The gene can change the body, but nothing can change the gene. Genes can mutate, that is change themselves of their own accord. Genetic modification, about which there is so much controversy, does not mean changing the gene; it involves planting an alien gene in the body in order to see what happens. The Michurinist school believes in the inheritance of acquired characteristics. One breeds from racehorses which have been trained to be good at racing. Firstly, characteristics can be acquired. Secondly, they can be inherited.

In *The Actuary* for February 1992, Professor Hans Eysenck was interviewed by consulting editor Peter Tompkins of this Institute. By the use of much data, Eysenck had identified a close correspondence between personality and one or other of eight innate disorders, which are: depression; drug addiction; rheumatoid arthritis; stomach and duodenal ulcers; hypertonia; diabetes; infarction and stroke; and cancer. A personality questionnaire was supplied. Actuaries may be interested to learn that if they are very logical then they are probably liable to depression.

Eysenck was investigating the possibility of curing patients by inducing personality change with their co-operation. This would represent a great advance. Human beings have the gift of language and can therefore think. They are qualitatively different from all other living creatures.

There is a correspondence between personality and a tendency to certain innate disorders, and a correspondence between genetic make-up and a tendency to certain innate disorders. Thus, there is a correspondence between personality and genetic make-up. Changing personality means changing genetic make-up. This is all the more remarkable, in that 30 or so years ago Eysenck was widely regarded as an arch genetic determinist — you have got the genes and there is nothing that you can do about them. His lectures were picketed, because he appeared to maintain that black people were genetically less intelligent than white people.

Remember here that, at present, a gene cannot be changed. It is not much use to say that we have discovered the gene responsible for cancer, unless we can do something about that gene. It may be that we can best approach genetic problems via the personality change road. So what am I advocating?

(1) Reprint the February 1992 Tompkins-Eysenck interview in *The Actuary*. This needs doing anyway, as it was marred by printing errors which had to be corrected in the March 1992 issue.

(2) Find out what progress Eysenck, or his successors, have made; the result to be reported in *The Actuary*.

(3) As proved in the paper, mutuality cannot buck the market. However, mutuality needs as its basis a greater measure of solidarity than we have at present. Solidarity applies not only to hospitals, railways, welfare benefits, etc., but also to all-round genetic research. More money must be spent.

(4) If someone has had a genetic test and has discovered a tendency towards cancer, insurance companies rightly want to know. Insurance need not be withheld if the individual can show that he or she is taking action against actually developing cancer.

Mr G. Whittaker, F.I.A., F.I.A.A. (in a written contribution, an edited version of which was read to the meeting)**:** I am writing as an expatriate British resident in Melbourne for more than half my life. During the last three years I have been involved with the Australian equivalent of the U.K. genetics and insurance debate, being a co-author of the book *Genetics and Society* (Doble *et al*., 2001), serving on related IAA, Investment and Financial Services Association (IFSA) and government committees. My career background includes life insurance, superannuation, underwriting and claims management, and industry matters such as mortality statistics, HIV/AIDS and genetics.

The Structure of these Comments

The main Australian sources for this contribution are the recent Australian inquiry discussion paper (ALRC, 2002), together with the written submissions of the IAA, the IFSA and myself. I will comment on the paper under discussion by reference to the emerging Australian approach to human genetics and insurance, which has gained particularly from the corresponding U.K. approach and experience.

I first describe the current Australian inquiry into 'Protection of Human Genetic Information', indicating the likely direction of its insurance recommendations, together with the existing legal requirement under the Disability Discrimination Act, to justify non-standard insurance pricing and terms, which are as a result of underwriting and risk classification factors. I then continue by commenting on the paper and on the U.K. genetics and insurance scenario.

The Australian Inquiry

In February 2001, the details of a Federal Government inquiry entitled 'Protection of Human Genetic Information' was announced by a joint reference from the Attorney General of Australia and from the Minister for Health and Aged Care to both the Australian Law Reform Commission (ALRC) and to the Australian Health Ethics Committee (AHEC) of the National Health and Medical Research Council. After an extension of time, the final report of the inquiry is due by 31 March 2003. The report will be published and made public. As it will contain proposals for law reform by the Federal, State and Territory Governments, it will be most interesting to see what changes eventually take place, with the Federal Government leading.

I have been serving as the only actuary on the advisory committee to the inquiry, rubbing shoulders with judges, lawyers, geneticists, ethicists, doctors, anti-discrimination and privacy commissioners, forensic medicine specialists, as well as consumer and industry representatives. An *Issues Paper* (ALRC, 2001) was released by the inquiry in October 2001 and a *Discussion Paper* (ALRC, 2002) in August 2002.

The specific drivers for the establishment of the inquiry were concerns about privacy and discrimination, especially in the context of employment and insurance. However, the terms of reference were much wider, to include the use of human genetic information by a number of sectors, including employment, health, medical research, pharmaceuticals, insurance, superannuation, intellectual property and law enforcement. The wide terms have been an advantage for how insurance law reform has been researched and treated. While ALRC (2001) set out the main issues, encouraging public participation and submissions, ALRC (2002) articulated the inquiry's thinking in the form of specific reform options. There followed a further round of consultation and submissions, recently completed. The final report is currently being drafted.

The Current Australian Level of Proof Required to Justify Medical Underwriting

Under the Disability Discrimination Act 1992:

> "It is unlawful for a person who ... provides ... services ... to discriminate against another person on the grounds of the other person's disability:
> (i) by refusing to provide the other person ... with the services ... or
> (ii) in the terms and conditions ... or
> (iii) in the manner in which the first-mentioned person provides those services."

For superannuation and insurance:

"This Part does not render it unlawful for a person to discriminate against another person, on the grounds of the other person's disability, by refusing to offer the other person:

(a) an annuity; or (b) a life insurance policy; or (c) a policy of insurance against accident or any other policy of insurance; or (d) membership of a superannuation or provided fund ...

If the discrimination:

(i) is based on actuarial or statistical data on which it is reasonable for the first mentioned person to rely; and

(ii) is reasonable having regard to the matter of the data and other relevant factors, or in a case where no such actuarial or statistical data is available and cannot reasonably be obtained — the discrimination is reasonable having regard to any other relevant factors."

The same exemption applies to the terms and conditions in which the service is offered.

This exemption effectively preserves the 'right to underwrite' for life insurers, general insurers and superannuation/ pension funds, provided that the underwriting of the death or disability etc. risk is reasonably based on statistics or other relevant factors (such as expert medical, actuarial or other professional opinion). The actuarial and life insurance industry representatives were successful in requesting the additional wording to deal with the common situation where supporting statistics are sparse or not available.

Thus, the level of proof is lower in Australia than is currently being applied in the U.K. to justify the use of genetic tests.

The Likely Findings of the Inquiry

The inquiry has formed the preliminary view that there is no demonstrated need to depart from the fundamental principle underlying the market in voluntary, mutually rated personal insurance in Australia, namely equality of information between the applicant and the insurer.

However, a range of issues are addressed that are directed to ensuring that the use of genetic information by insurers is fair and transparent, and that insurers are kept to the terms of the exemption granted to them by anti-discrimination laws. So, while the preliminary view is that genetic information should not have a fundamentally different set of rules, action is proposed so that the existing rules, with some modifications, are properly applied, especially where genetic information is concerned.

Having said this, the question is raised: "Should there be a fundamental change to the way in which genetic information is used to underwrite personal insurance, such as the introduction of a two-tier system; a prohibition on the use of genetic information; or a public subsidy for poorer risks?"

Consequently, these options have still been left open for political consideration, despite not being the preferred options of the inquiry.

The specific issues and proposals for reform include:

(A) The proposed Human Genetics Commission of Australia (HGCA) should monitor the experience of the insurance industry in using genetic information in underwriting, both in Australia and overseas, with a view to reviewing Australian insurance practices at a later time.

(B) No predictive genetic test should be used by insurers in underwriting mutually rated insurance, unless the test has been approved for that purpose by the proposed HGCA.

(C) The insurance industry, through its peak bodies and in consultation with the proposed HGCA, should develop and publish policies on the use of family history for underwriting mutually rated policies.

(D) Where an unfavourable underwriting decision is based on genetic information, the insurer should give reasons that are clear and meaningful and explain the actuarial or statistical basis for the decision ... (My comment: 'or other basis' wording, in line with the DDA exemption, needs to be added.)
(E) The insurance industry ... should develop appropriate mechanisms for reviewing underwriting decisions involving the use of genetic information...
(F) The insurance industry should review its policies and practices in relation to the training and education of industry members and their authorised representatives in relation to the nature, collection and use of genetic information in insurance.

Do we hear echoes from the motherland of 'freedom with disclosure'?

Some Observations on Genetic versus Other Information

A vital point is that the inquiry has not, so far, provided a detailed definition of 'genetic test', although, at least for insurance regulation, such a definition will be needed for the relevant classes of tests that can be understood by client, agent, doctor and underwriter. One example of a definition is the 'scientific definition' used in the existing IFSA Code of Practice for Genetics and Insurance, but that will need refining. Another, or additional, approach to the definitional issue may be to define broadly, within a scientific definition, the subclass of genetic tests that are used by the medical profession for diagnostic or prognostic purposes. IFSA has developed and maintained a de-identified industry database of genetic tests disclosed in relation to particular life insurance applicants. As well as providing vital monitoring data, analysis of the data by type of test is most interesting to see what types are being disclosed in practice.

So far the most common are those for haemochromatosis, Huntington's disease and breast cancer, comprising some 86% of those disclosed over a two-year plus period. It is also interesting to note that no tests have been disclosed for congenital defects in the newborn (standard practice in Australia for treatable defects in all the newborn, and also used for diagnostic purposes in the event of significant actual and potential health problems), nor those for significant sex chromosomal abnormalities. Abnormal tests performed in utero, where a baby is subsequently born live with a significant defect, would also be relevant to insurers. Of course the applicant often will not be aware of such tests, or the medical condition may be disclosed. While less than 300 tests have so far been disclosed, the numbers may be expected to grow in future, as genetic-type tests become more significant in medical practice.

The crux of the insurance debate worldwide is the extent to which genetic tests and genetic information differs from other forms of medical tests and individual human characteristics (e.g. cholesterol, status of health of a body organ, or a specific disease/disability). Severe mental illness, HIV/AIDS, syphilis, or leprosy of a father, may be just as sensitive an issue for wife and children as a monogenic or other type of heritable genetic defect in the father. Privacy legislation, doctors and underwriters view all individual medical information as confidential and sensitive.

Comments on the Paper and the U.K. Genetics and Insurance Scenario

(A) The paper is an excellent study of the U.K. scenario, with a well argued discussion about the alternative levels of evidence and modelling techniques that can be used to support underwriting guidelines involving specific genetic disorders, tests and family history. It is also very helpful to actuaries in Australia, where there has been even less research into statistical justification for underwriting practice. The emphasis, however, is on the current U.K. political realities. The paper structure, analytical approach, 'looking to the future' and conclusions are excellent.
(B) The Australian scenario is not the same, although similar, and the recommended insurance model likely to emerge from the Australian Genetics and Discrimination Inquiry is different. The comparison of this approach with that of the U.K. is most interesting to actuaries and others in both countries, even before the final report and the politicians' reaction to it.

(C) The stark difference is the degree of justification being demanded by the U.K. authorities for the use of genetic tests when compared with the traditional approach for other types of medical evidence and risk factors and with the proposed new Australian model, with its emphases on public education, openness, transparency, accountability, complaints procedures, insurance application database, and equity with others who have medical risks.

(D) The described mathematical models developed in the U.K. for monogenic disorders can be compared with the traditional numerical rating system models (for both life and general insurance). The multi-state models, although very useful as theoretical models for the rare monogenic diseases, are very demanding of data and professional estimates. However, for most known and new risks, 'best estimates' based on medical knowledge/opinion and emerging statistics may still be the more practical and understandable approach. Underwriting guidelines have always been 'multifactorial' in nature, and for a multifactorial disease such as breast cancer, the traditional model (perhaps with some sophistication grafted on) is still being relied on. From what I glean from the paper, the multi-state model alone may not be suitable for multifactorial risks. Perhaps we, as actuaries, have overcomplicated the publicised modelling process (in our response to public concern for the monogenic disease potential victims and the GAIC process constraints including hurdles of proof).

(E) The GAIC hurdle of proof is both impractical for use, as genetic knowledge extends, and also at complete odds with that used for other medical and non-medical risks. The insurance industry might grind to a halt if the higher hurdle were imposed across the board. The paper, in its analytical and well argued way, may be read as requesting that the U.K. genetic test hurdle be lowered, having served its purpose.

A vital issue remains, therefore: "What should the hurdle of proof level be; the traditional, or some new, modified level? Should that level be the same for all risks?"

(F) The 'numerical rating model' for extra and reduced risks from 'standard' (an actuarial methodology), with its 'plug-in' variations such as constant and declining risks, has stood the test of time remarkably, at least in the reinsurer-produced underwriting manuals most used by life insurers.

In contrast, there is the development of 'expert systems' used as assistants by some medical specialists and senior underwriters. These systems reflect the real-life complexity of medical diagnosis and prognosis (together with the parallel underwriting issues when estimating mortality and morbidity futures). While the numerical underwriting system can be seen as a simplified version of the whole set of expert underwriting models for different diseases, it can now be considered oversimplified for some applications where medical knowledge of the effects of multiple parameters on disease diagnosis and outcomes has progressed significantly.

The challenge, then, for the actuarial profession, led by mathematical modellers such as Macdonald and Wilkie, but with greater input from actuaries with practical underwriting experience and from underwriters, is to produce revised/enhanced underwriting models tailored to the practical needs of the worldwide life insurance industry and its clients. In doing so there are issues of feasibility, cost, practicality and understandability to be considered. This challenge is for the whole field of underwriting, not just for so-called genetic risks.

It is likely that most diseases will turn out to have some genetic factors. Perhaps all disease is multifactorial, including both genetic and other factors. As such, the current political genetics and insurance storm may calm down in the light of scientific knowledge and better education.

(G) While the medical profession and genetic scientists necessarily take the lead, actuaries can assist them by designing multivariate parameter models that can be used with available data and statistics and with very large inputs of informed professional judgement that can provide a better 'forecasting likely futures' task. For underwriters, the models will provide

some different output, namely a best estimate of extra risk for life insurance pricing purposes.

(H) We, in Australia, have advocated that the life insurance industry, in its underwriting practices, should follow (rather than lead) medical knowledge and practice. In our view the ideal wider jurisdictional model is that where genetic tests and information are well controlled (but in an equitable way in relation to other tests, disability and disease), and where the defined levels of proof to justify underwriting practice are practical, rather than over-demanding. A good test of levels of underwriting proof is to perform a comparison of those required by the medical profession for medical treatments. If a particular genetic test is made available for diagnostic and prognostic use, it should not be too difficult to produce rough, but practical, estimates of future additional risk for the range of values of the parametric results of the new test.

These estimates can be updated as experience, statistics, research and knowledge develop, with more sophisticated models as and when feasible.

This, after all, follows the traditional insurance business approach to new risks, but with added sophistication.

References

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Mr R. G. Thomas, F.I.A.: I have no connection with the insurance industry. In the HGC consultation in 2001 I made a submission which was critical of the industry and of our profession. In it I explained that the profession's contributions to this subject over the years have been largely malign, and some contributions have made me feel ashamed to be an actuary.

The subtitle of the paper refers to social policy issues, but the paper avoids discussing many social policy issues which I would regard as important. This is particularly striking in Sections 5.2 and 5.5, where we find commercial arguments for the industry carefully set out, but there are no corresponding sections for the arguments of anyone else.

One key social policy issue is the concern that the use of tests in insurance is likely to have an adverse effect on clinical medical practice, that is people will be deterred from taking tests and from discussing them with doctors because of worry about the insurance implications. That is a profoundly important public health issue, but is not discussed in the paper. In 2001 the HGC found evidence that this was already happening. Another social policy issue is whether the moratorium is adequate or whether, as the HGC suggested, it needs to be statutory to make insurers take it seriously. It should be statutory, as self-regulation in the insurance industry has an awful track record.

Turning to the suggested way forward set out in Section 5.6. The first sentence of that section starts "One practical way forward for insurers ...". The authors then note that attempts to justify genetic tests by statistical significance are likely to be very difficult, so they suggest that we fall back on a vague notion of 'vulnerability'. That seems very woolly to me; it seems as if it is intended to be able to mean whatever the insurance industry wants it to mean. That completely fails the test of openness and transparency, which is referred to elsewhere in the paper. I hope that the HGC and other authorities will have nothing to do with it, or at least set very tight limits on its interpretation.

Picking up on some other points in the paper: ¶3.5(f) talks about a premium increase of 1%, and then says that is quite high. Quite high in relation to what? When I looked at market premiums for a simple term assurance, which is the closest thing that we have to a commodity product, I found that for a given life the best half a dozen rates seem to vary by up to 40%. The market appears very imperfect and very uncompetitive. In that context, modelling which shows an increase of 1% or even 10% seems neither here nor there.

I am retired now, and spend time thinking about investment decisions. As an investor I am not concerned with what I want to happen, I am just trying to figure out what will happen, and position myself appropriately. Looking at this subject from that perspective, I see an overwhelming public revulsion towards genetic testing in insurance, not just in the U.K., but in many other countries. That revulsion is not freestanding nor idiosyncratic, it is part of a global tide of greater emphasis on individual human rights. Set against that, I see one industry and one small profession which appear to be always and everywhere hostile towards human rights, and which wish to swim against the tide, which is a losing strategy. The tide is against the profession, and the long-term future on this subject is one of slow retreat. There may appear to be short-term gains in particular jurisdictions, as you thought there were with the establishment of GAIC, as it sounded from earlier contributions that there might be in Australia at the moment; but the long-term trend is quite clear. That is why I have been very comfortable taking a contrarian position within this profession on this subject. Not only is it the right thing to do, it is also very likely to be vindicated by trends which are more powerful than this profession — and indeed, over the past few years it has already been vindicated by those trends.

Miss F. J. Morrison, F.I.A.: This paper is concerned with social policy issues, and my comments view these matters from the customer's perspective, about: 'dancing on pin heads'; 'cliffs' in insurance; and the customer's perspective of being forced to take a genetic test.

The first thing that struck me about this paper was the level of detail looked at in terms of genetic tests, which is the 'dancing on a pin head'. The paper questions why there should be such a focus on genetic testing when rating, arising from existing underwriting by reference, for example, to family history, is not affected. In a world where we read daily of medical advances, and in which transparency is increasingly important, traditional rating and underwriting are opaque and no longer sustainable.

So, my first challenge to the actuarial profession is the extent to which we should be working with underwriters, to gather reliable information and to ensure that their current rating systems are fair and reasonable and can become understandable and transparent to customers. For example, according to medical websites, the increased chance (at a certain age) of developing breast cancer with a family history of one's only sibling having had the disease is 50%, or 60% higher than someone without that family history. Does it look odd to find a suggestion that a 100% loading is required for long-term sickness cover? Couple that with being a non-smoker, apparently very fit, with a good heart, etc., and the customer concludes that she may be bringing different risks to the pool than the average, but she is not convinced that she is bringing higher risks to the pool than the average. So, what is a rating doing, looking at the individual as a whole, or cherry picking additional risks without giving credit for the lower risks?

Pursuing this in more detail, where are the statistics that show how much of the premium relates to the morbidity of breast cancer cases (as opposed to all the other causes at that age)? So far as I can tell, the answer is that the statistics do not exist. So let us go back to the loading. A fair outcome certainly does not seem to be a 100% loading. With proper morbidity statistics, the underwriter might be able to argue that a small loading is required, rather than acceptance at normal rates. (Normal rates eventually applied in the example that I have mentioned.) Why is it such a big issue not to pay a loading? Surely not the cost of a modest increase in premium. No, but it brings me to my second theme, that of 'cliffs' within the current world.

The perception is of meeting a cliff; if the customer has been loaded in relation to one insurance policy, then he or she would never again be underwritten at normal rates. That is very

threatening to an individual, and when the individual can make some assessments, and believes that overall she is not a greater risk than many in the population, it seems both illogical and unfair. Another 'cliff' is actually caused by the current moratorium. Is the moratorium the only 'window of opportunity' for such an individual to obtain insurance (as she might be forced to take a genetic test after the end of the moratorium)?

That brings me to my third comment, the impact of enforced tests, perhaps at the end of the moratorium to which the opener alluded. My husband (a doctor) always says: "You should only take a test if there is a course of action which will be followed with a particular result which would not otherwise be followed." Putting that into the context of what we are discussing and the customer's perspective, the customer's first reaction upon the diagnosis of the illness of her sibling is to want a genetic test. She then finds out more, and, as stated in the paper, only 5% of cases are apparently linked to BRAC1 and BRAC2, so a clear genetic test does not mean that she is clear. Then she considers the medical treatments, and finds out that there is no difference in treatment whether she knows or not. So, from that customer's position, with no potential medical treatment, she might not want to have a genetic test.

Then I consider the industry. It seems to be an arrogant industry which might force a test to be taken in those circumstances, in the context of my example and not in the context of a situation where there would be medical treatments which would be linked to the results of a genetic test. The industry must accept that there will be massive opposition to enforced tests for the types of situation in my example.

Mr A. W. Doble, F.I.A., F.I.A.A. (in a written contribution, an edited version of which was read to the meeting)**:**

The Actuarial Profession and Public Policy

I had a 'Road to Damascus' experience in 1980. I had just accepted a job as a superannuation actuary, when my new boss said to me: "I hope you realise, Alan, that when you chose to become an actuary you were choosing a career in sales?" Well, I had not realised that before, and I did not believe it at the time, but it has turned out to be absolutely true.

When the actuarial profession steps into the field of public policy it should be there to sell, that is selling our ability to weigh up conflicting views and help the public to make wise and well informed decisions. That is how we inform public debate. We can only meet our goals in public policy if we form considered opinions. Unless we have a point of view, we have nothing to sell. Social policy is hard work, precisely because there is such a variety of ideas to balance. Just like any other group of men and women, individual actuaries will hold individual views. Some actuaries will not like it when the Institute and the Faculty form views that they do not personally support, but it should be the role of the Social Policy Board to take a stand.

Has the Genetics Group gone far enough in forming views on genetics and insurance? I think not. You present all sides of every argument on genetics and insurance in a most lucid and well balanced way; but where are your conclusions? Where is the passion?

KISS

Our Australian paper on genetics (Doble *et al.*, 2001) paid tribute to the mathematical modelling being pioneered in the U.K. by Professors Macdonald and Wilkie and the team at Heriot-Watt University, but I am not sure if it is the best way of evaluating genetic tests for use in underwriting.

Is there any reason to discard the simple model of extra risk behind the numerical rating basis? When actuaries have looked at hazardous pastimes or occupations, at places of residence or non-genetic medical conditions, they have not needed to use multi-state Markov models. Scientists talk of Occam's razor, but almost everyone knows of the KISS principle, 'Keep it simple, stupid'.

If someone has a higher than average chance of falling sick or dying, then they also have a higher probability of claiming under their disability or life insurance policy. As long as

experienced doctors and medical researchers can estimate how much higher that probability is, the insurance actuary can calculate how much higher the premium should be to cover that risk. That is the simple principle on which underwriting manuals have been built for more than a hundred years. Why should the approach to genetic diseases be more complicated?

Unfair Discrimination in Favour of Genetic Illnesses

Insurance is a commercial activity. Insurance underwriting in the U.K. has become unfairly biased in favour of genetic illnesses, as genetic factors now have to be treated more leniently than other risk factors. Why should an insurer be forced to sit on its hands when an applicant for insurance has found out that he or she has a higher probability of making a claim through a genetic testing process? If the applicant knows that they are at higher risk through any other cause, they must disclose it. The principle of symmetry of knowledge is so important to a sound insurance market that most countries enshrine it in law. The insurance company is given legal remedies if it finds itself the victim of non-disclosure.

Some eminent thinkers hold views contrary to your position in the U.K. Thomas Murray is the Chair of the task force on Genetic Information and Insurance under the Committee on Ethical Legal and Social Implications of the Human Genome Project (the ELSI Committee). Murray's task force studied these issues and concluded that:

> "there was no good moral justification for treating genetic information, genetic diseases, or genetic risk factors as categorically different from other medical information, diseases or risk factors."

I agree that an insurance premium should only be loaded if there is reasonable evidence that the probability of claim will be higher than usual. How should that probability be established where the disease is genetic? Is the fact that a genetic test has been released for medical use a prima facie evidence that higher risk exists? A doctor would not order a genetic test for no reason. Nor will a test be used if it cannot show anything useful. Also, if a gene mutation has no ill effect, there is no point testing for it. So, how did the U.K. insurance industry get caught with having to jump a higher hurdle than the medical profession? Who approves the use of genetic tests in medicine? Why is the proof already given to the guardians of the medical profession not enough for the guardians of the insurance industry?

Multi-Factorial Conditions

Section 3.5 includes misleading wording, saying that: "Multi-factorial disorders are unlikely to be of much significance for life insurance." That is too sweeping a statement, since heart disease and cancer are the two leading causes of insurance claims. I think that what the authors meant to say is that there are no multi-factorial genetic illnesses likely to lead to conclusive genetic tests in the near future. If that is really your view, I can see trouble ahead.

Let us consider just one multi-factorial condition, coronary arterial heart disease. Every doctor accepts that there is a familial aspect to heart disease. It is undoubtedly partly genetic. Factors indicating increased risk of heart disease include raised blood pressure, high cholesterol, obesity and smoking. Taking a person's blood pressure and arranging for biochemical testing of blood and urine samples are routine processes with a proposal for an insurance policy of reasonable size. All applicants will almost certainly be asked if they are a smoker or not. Within the next decade, I expect that there will be breakthroughs in finding which genes are associated with raised blood pressure or raised cholesterol. Far more speculative, but still possible, some researchers expect to be able to show that behaviours such as smoking may also be affected by a person's genes. Surely, one day the argument will be put that cholesterol, blood pressure and smoking are therefore genetic test results. Will the U.K. insurance industry and the actuarial profession be so relaxed then? Logically, since you have voluntarily given up asking for genetic test results, will you also have to agree that you will no longer ask questions on those very clear and well established adverse risk factors?

Asking for your Gifts back

Everyone who has a child will know that, once a concession has been given it cannot be withdrawn. I was surprised when I learned that the ABI had conceded a moratorium against the use of genetic test results. I fear that what has been given away will never be regained. There has to be a good chance that the British insurance industry will never now be able to ask for existing genetic test results for most genetic conditions and for most types of policies. The ABI seems to have thought that this was only a small concession, since there were not many genetic tests then in use. And even if there was blatant anti-selection, the losses caused to insurers would not be very large.

What has happened since? First, the 'small' policy concession has become much bigger. Basing my calculations on relativities with Australia, I would guess that the new limit of half a million pounds may be about six times average policy size. Second, the concession that was only going to be for mortgage-related policies now applies to all policies. What started as a chink in the door is now big enough to drive a lorry through. If U.K. insurers have to give up cholesterol and blood testing, the gap will be wide enough to let the largest ocean liner sail through.

Roll up to see the GAIC

The insurance industry accepted a moratorium, which it should have fought hard against. It also chose the wrong weapons to fight its battles (actuarial models that were so complicated that it was impossible to find statistics to build them). I now find, from ¶4.3.4, that it forgot to ask for a level playing field. The ABI agreed to pass the responsibility to GAIC to decide which genetic test results could be used; but GAIC has not worked. It accepted the first test for Huntington's disease, in October 2000. By December 2000 the insurance industry had completed a mountain of work in support of applications to use other genetic tests. After two years these have not even been considered! GAIC disbanded itself in 2001, and although it reformed in 2002, it still has not decided how it will do its job. This must have left the insurance industry stranded. I am reading between the lines here, but this paper gives no sign that the ABI, or the actuarial bodies, have done anything other than meekly accept this outrageous position.

What is happening in Australia

Why should the rest of the world care what happens in the U.K.? Because every Parliament looks at what overseas governments are doing. We have underway in Australia an extremely thorough government inquiry into the protection of human genetic information. That will have been running for more than two years when it presents its final report in April 2003. Australians are very interested in the decisions made in U.K., as well as those from North America and Europe. If someone makes a decision on one side of the world, the other side needs to work that much harder if it does not want to follow.

I will give you a couple of quotes to show you how the Australian inquiry is thinking. These are from Chapter 24 of the inquiry's second major book:

> "The Inquiry's preliminary view is that a shift away from the fundamental principles of voluntary risk-rated insurance, based on parity of information between the applicant and the insured, is not warranted at the present time." (Paragraph 24.87)
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> "There are a number of reasons for the Inquiry's preliminary view that there should be no fundamental change to the basis of underwriting applications that involve genetic information." (Paragraph 24.90. The paragraph then goes on to list those reasons.)

Equity and Fairness

Whether or not you agree with my views on underwriting, you might say that it is the job of the insurance industry to protect itself. You may think that it should be up to the ABI, and not the actuarial profession, to argue the case; but I still see actuaries as protectors of equity and fairness. It is because the arguments against the use of genetic test results are illogical and unfair that actuaries should be interested. It is because the issues are in an area where we are experts that we should be passionate.

This discussion should set a firmer direction. It is time for the U.K. profession to make up its mind and to go out and sell its conclusions.

Mr A. Kent (a visitor)**:** I am speaking in a personal capacity and from the perspective of someone who represents the families who are the ultimate consumers of the products of the insurance industry. Families who live with genetic disease want confidence that they can make reasonable arrangements to secure their long-term wealth and well-being in the face of excessive adverse circumstances. Historically the state has fulfilled that role, but now seems to be moving away from the notion of social solidarity towards individual responsibility, so that we each have to make arrangements to meet our own long-term needs.

The debate around genetics in insurance is an important one, because in many ways it reinforces the validity of that route to individual responsibility. It shifts us away from expecting that we all have a contribution to make to one another's well-being when faced with circumstances of adversity that are not of our choosing. The debate about genetics is driven by an unfounded belief in its power. Validating that power by concentrating on the issues, by teasing out all the small print, by going through the process that we are going through, over-emphasises the part that genetic factors will play in considerations to do with insurance, and it also validates the belief of the power of genetics in other areas of life. We need to worry about it in life terms, for example access to medical care, plans for employment, and so on. That feeds into the fear of unfair discrimination that many people have when thinking about the impact that their genes will have on their life opportunities.

There are two things that we can do to address this. We can educate or we can regulate. At the moment regulation seems to be the preferred solution, whereas education seems to be very much a poor relation. There is not enough knowledge to regulate accurately and sufficiently. If we do regulate we are validating the power of genetics in people's minds and giving it a weight that, perhaps, it does not warrant.

In the long term we need to reach a more balanced view of genetics. Not all genetics is like Huntington's disease, or breast cancer, or familial Alzheimer's, which are three standard deviations from the mean, and there is a danger that too hasty a rush to regulation will end up with the actuarial equivalent of the Dangerous Dogs Act, and we will need to define whatever the actuarial equivalent of a rottweiler is. If we move towards educating, recognising the legitimacy of public anxiety about the potential for misuse, and a recognition of that legitimacy, and then try to understand why people are concerned, taking their anxieties with us towards a more balanced conclusion, we have a better opportunity of putting genetics in the context of insurance in a box that is of an appropriate size.

The families who live with genetic disorders are, by and large, reasonable people. What they want is to have confidence that when they find themselves, through no fault of their own, in a situation where they are at a disadvantage, because of their genes and of their risk of a genetic disease, that they will be treated fairly by everyone whom they meet, not just the private insurance market, but also the public sector and the healthcare system. They want to be confident that, if in a strictly commercially driven private market avenues are closed off to them, then other avenues will remain open so that they, just as everybody else, will be able to face a future where they can be reasonably confident that their hopes for wealth and well-being, sufficient to meet their needs in a comfortable way, will be met, either through their own efforts or as a consequence of the organised efforts of society to support those for whom the individual route is not an option. Finding a method that would enable us to get to that point would be good for society and the insurance industry, because it would give us all confidence that we were not dependent on the vagaries and the whims of the marketplace. Alternatively, the answer for those who identifiably suffer from severe genetic disadvantage could be national insurance.

Mr M. N. Urmston, F.I.A.: This excellent paper summarises the state of the art so far as genetics goes. The insurance industry wants to move on from where we are. Despite the contributions from Australia, we have accepted that the world has spoken, society has spoken,

about this issue in such a way that says: "We do not wish you to take account of genetic tests for the vast majority of people." A moratorium in those circumstances is probably the most sensible position to be in, but is unhelpful in looking at the future of both insurance and the future of genetics. The collection of proper data on genetic conditions cannot be achieved easily while moratoria of this type are involved. We are not collecting any data whatsoever about genetic tests. We need to move to a situation, when that moratorium is replaced, which is equivalent to a moratorium, but allows the collection of data in a logical and a reasoned way, while protecting the interests of all consumers. This would provide an opportunity for the profession to carry out academic work, the sort of work that Professor Macdonald is doing at Heriot-Watt University, both there and, we hope, elsewhere within the university world. The actuarial profession has not yet set the appropriate standards for that sort of work, to set the peer-reviewed type of professional standards that we would normally find in other scientific work, and we need to address these standards.

A phrase in the paper, which is much used, states that people should not be penalised because of their genes. The industry has accepted that position. You could look at this from a different point of view. Should people actually gain benefit because of their genes? The alternative question may not always get the same answer. We have seen clamour for negative tests to be taken into account in insurance. We can envisage a situation where annuities could be better for people with genetic conditions. That is not saying that we are getting there, but it is only a matter of time.

Insurance is not just a matter of underwriting. We are writing long-term ten, 20-year contracts for term insurance, long-term care and critical illness. Those contracts are renewed every year. As science changes, the policyholders have the option to renew or not to renew on terms which are guaranteed by the life insurance office. We are already starting to be exceedingly concerned about guarantees on long-term critical illness. When will we be concerned about guarantees on long-term term assurance? At some point we may be. Not to have data and not to do analysis is the wrong approach.

The public has lost trust in the insurance industry, but the involvement of academics and actuaries can help with the analysis of this sort of information.

If we are uncomfortable about wider underwriting practices, then we ought to be doing more research into the scientific analysis of different types of underwriting, whether they be medical, family history, or whatever.

Mr P. J. Turvey, F.I.A.: One issue which has come out of the discussion so far is social policy. The answers to a lot of the actuarial questions that we have been discussing depend on the assumption that you make at the start regarding social policy. Mr Thomas is a logical person, and no doubt has thought his positions out carefully. In social policy issues he and I would be a mile apart. If we start with different assumptions regarding the appropriate social policy, we are not going to end up at the same point when we are trying to apply actuarial thinking to a particular question. The answers as to what we ought to be doing with genetics and insurance and all the issues that we have been discussing depend on where you start on social policy. Social policy should be discussed, as well as the actuarial issues, to achieve a clear understanding of what is involved.

An example is the model for motor insurance. We are happy when it comes to motor insurance. You phone up the insurer, you give him your age, the number of speeding fines you have had, where you live, what kind of a car you have, how many miles you drive, and on and on. Nobody says that that is intrusive, or that you should not be asked how many miles a year you drive. You accept it. You hear them pressing the buttons on the computer and out comes the premium rate that they want to charge you for your motor insurance. We accept that. It is a black box. We accept that it is a black box, because we can telephone another six insurers during the day and we will get a choice of six premiums. We can take the best premium and we are pretty satisfied at the end. I have no idea how that black box worked, or the multiple regression analysis that went on behind it. What is wrong with that as a model for genetic impairment? You have a particular gene, you go to a broker, the broker places matters in front of a few life

offices. Each life office goes to its favourite reinsurer, or rating manual, and comes back with an answer. You then have a choice of rates, and can choose the best one. If you start with a particular set of assumptions as to your social policy priorities, you might well conclude that that was a better solution than some of the other ones that we have been discussing.

Mr P. J. Nowell, F.I.A.: The main point that I want to focus on is the subject of longevity, which Mr Urmston touched on. In this paper, and in the general discussion about genetics, there is relatively little discussion on longevity. Longevity is of much greater risk to the insurance industry in the longer term because of the amount of annuity and pension business that it has on its books. For example, some types of genetic make up could indicate survival to advanced ages. If companies started to price using genetic testing, and if a person could score well for survival, then he would have some good news and some bad news. The good news would be that he should live for a long time, but the bad news would be that his annuity would be expensive. On the other hand, the person with the wrong genetic make up would be pleased that he could buy a very big pension with his cash lump sum, but the bad news would be that he may not claim it for very long. This balance of good news and bad news contrasts with the 'bad news, bad news/good news, good news' situation in life assurance, so there is at least more balance of interest when you consider annuities. We need to know if genetic make up, or indeed genetic engineering, could be important in longevity in the future. As medical advances and the adoption of healthier lifestyles reduce premature death, genetic causes must become more important than they are now in how long people live, particularly at older ages. What I have been hearing in the discussion is that genetics may not be a major issue in profit terms, or risk terms, for U.K. life assurance companies at the moment, and therefore there is time to worry about these things later. Are we missing the issue in concentrating on life assurance? Or should we be trying to understand the potential impact of genetics on longevity post 65 years old?

Mr R. Walsh (a visitor; Head of Health Insurance, Association of British Insurers)**:** I want to respond to a few of the points that have been made. Firstly there are the contributions from Australia. They have their own debate in Australia and we have our own in the U.K. If you look at what is happening in Europe, many European countries have a moratorium as we do. Ireland is a good example. Other countries ban the use of genetic tests. Some even ban the use of family history, and as a result have no critical illness market. Other countries allow the free use of genetic tests as in normal medical information. There is a debate in every country. These differ, because the underlying factors that create the situation in each country, as Mr Turvey said, are around social policy issues. The ethics and history of each country, and the insurance systems in each country, are different. So, while it is very interesting to hear what is happening in Australia, and we have certainly learnt from different countries in their approaches, to assume that one country's approach is superior to another country's approach is wrong.

One criticism of the paper was that it was a way forward for insurers. It does actually cover quite a few of the social policy issues. Nevertheless, it is a paper by the Institute of Actuaries, and it is that stakeholder group's position on this issue, just as it would be perfectly valid for other stakeholders to put forward their positions based on their particular concerns. That is one of the really big things about the genetics debate, and why it is different. There are so many different stakeholders involved, the Human Genetics Commission, the Government Genetics and Insurance Committee, genetics interest groups, special interest groups, the media, the research establishments, the Department of Health and the NHS, the Treasury, the Office of Science and Technology, the geneticists, the epidemiologists, the actuaries, and the GPs, all coming from different perspectives. The moratorium in the U.K. has encouraged a rational debate. We should continue to have that, and I welcome the work that the U.K. Forum on Genetics and Insurance has been doing to take that forward.

In terms of the future, the moratorium has another three and a half years to run. We need to be thinking about what should replace it. The Government committed itself, in responding to the Science and Technology Committee report, to consult on this issue. They have not done so yet, probably because they have been doing their own work about what their thoughts on the future

might be. I am sure that the HGC, too, will be involved in the process. We are waiting for them to engage in the consultation exercise. That is not to say that we have not been doing anything. We have been very active on the family history front in submitting evidence to the HGC on why we should be continuing to be able to use that, and we take a full part in the U.K.FGI debates and other debates, such as this one.

The other problem with this issue is that nobody really knows what the future is going to bring. There are three scenarios. The first is where very few tests are actually relevant for insurance purposes, as few people take them. Secondly, there is a situation where more people start taking the tests which could be relevant for insurance purposes, and you start to build up a critical mass of people who, with adverse selection, could impact on the industry and its solvency margins. This is the kind of work that Professor Macdonald has been very helpful in developing in his modelling.

Where will we be in three and a half years' time? I do not think that we are going to be in the third scenario, which is the one where everybody has genetic tests and everything is relevant to insurance. We are far from this point, if ever we get into that situation, and there is a view that we never will; but in three and a half years' time we will be in the situation where still we will not have any information at all about the number of people with positive tests who are taking out insurance, and what levels of insurance they are taking out. That may be okay if there has been no real change in the numbers of people taking tests, but, if it turns out not to be like that, then that is quite a dangerous position to be in. Therefore, you come to a situation, as Mr Urmston was suggesting, where we have to have some form of information. If there is going to be that information, what information should be held and who should hold it, and all those sorts of things? That is all for the future. We have to wait now until the Government gets the consultation process under way, and the outcome of this process.

Mr D. I. W. Reynolds, F.I.A.: I work in life insurance, and do not think that we are debating an issue that is actuarial. Gathering and analysing the data are essential before it is an actuarial issue. We are debating social issues and, in particular, the distinction between solidarity and mutuality. There is particular concern about genetics, and a choice between regulation and education. Education is vital. The issue with genetics is that it cannot be seen and it is hard to understand, in particular the geneticists and the medical profession have not yet got to a stage where they fully understand the impact of genetic differences.

I should like to take a different example and use it to help broaden the debate into this solidarity versus mutuality issue. That example is flood insurance. Here we can expect continuing debate if a different group of scientists, not geneticists, are right about global warming, and that water levels, particularly around the east coast of the U.K., rise. Flood insurance will then become more difficult to buy for a greater proportion of the population. One can see the risks. One can measure the height above current sea level of the property that you own or are buying. It is less fearsome than genetics, but it is the same issue of mutuality or solidarity. If you live 2,000 feet above sea level, are you prepared to pay more for your insurance to cover those who choose to buy their property at sea level? That is a social issue. It is right that this paper talks about social policy issues. What we should encourage is a proper debate about the differences between mutuality and solidarity, and there will be cases where only national insurance is possible, and it may be that where that limit is will change over time.

I look forward to some of the current measures of discrimination of risk ceasing. Paragraph 2.3.3 mentions age and sex. It says that some people are arguing for unisex rates in various areas. I am looking forward to age discrimination regulation which prevents the use of age, so that I can get my medical expenses insurance much cheaper, and I will put up with the consequential higher motor insurance rates!

Ms H. Martin, F.I.A.A.: In Australia we have had a very balanced, open and considered debate and discussion on genetic issues. We have managed, so far, to strike a good balance between education and regulation that has allowed us to have the outcomes, the processes and the

arrangements that we have in place in the insurance industry at the moment. It has taken a lot of goodwill, and a lot of effort, on the part of all the stakeholders to come to a shared agreement. It is an issue of balance, addressing and agreeing as a community, and as a society, what your objectives and aims are, and what outcomes you wish to achieve, and then the best way of achieving them.

It is an issue of balance between what is the minimum level of cover, for example, that everyone is entitled to have at a reasonable price versus what they then choose to do on a voluntary basis. The arrangements and the rules and regulations that you would have for those two different things would be quite different. For example, this could be individual rating for the voluntary insurance, but pooled or social arrangements for the minimum level of cover at reasonable rates.

There is an issue of a balance between education and regulation. Actuaries could help by becoming a little bit more creative and working better with other disciplines, helping to generate the debate and discussion and forming a socially accepted and agreed view.

We need to be careful not to put genetics too much in its own box. It is just one of the risks to be considered in the insurance context, so we should be careful not to treat it differently to other health issues or other risk issues.

In Australia we achieved a mutually socially agreed outcome for medical defence insurance. There was a significant failure of a medical defence organisation in Australia recently, and there was a need to come up with alternative arrangements for the insurance of doctors who wanted to practise. What we have ended up with is a package that is a mix of risk rated insurance and socially pooled insurance, where, for most doctors, they get rated on the basis of their individual factors and the areas of medicine in which they practise and what the true risk to the insurer is for underwriting that doctor. However, there is a social agreement for some particular doctors, like neurosurgeons and obstetricians. The cost of the insurance for them, if they were individually rated, would be prohibitively high, and therefore they would not be able to practise. Everyone thinks that it is a good idea having neurosurgeons and obstetricians practising, and therefore the Government subsidises the cost of the insurance for those particular practitioners. So, that was a solution to an issue that needed to be addressed, but it was addressed by all the stakeholders communicating and agreeing what the minimum rights and obligations were for all those involved, the insurers, the doctors and the public, and hence what solution could be put together, as a package, that everyone agreed would address the concerns and issues and arrive at a reasonable outcome. I encourage you to continue your debate and discussion, take a balanced view, and address those important social policy issues.

Mr P. N. S. Clark, F.I.A.: Mr Kent, in his comments, distinguished between discrimination and unfair discrimination. Most people do not understand that distinction; in other words, all discrimination is assumed unfair by definition. Mr Urmston pointed out that genetic discrimination can be both positive and negative.

Since the late 1980s the profession has done much work on the subject of genetics. I join with Mr Doble in giving great credit to the work that Professor Macdonald and his team at Heriot-Watt University have done, and also the work that Mr Daykin and others have done in establishing the U.K. Forum for Genetics and Insurance.

I supported the introduction of a moratorium. I understand Mr Urmston's point about the lack of data, but it was far better to have a moratorium rather than, as Mr Kent said, the rush to regulation. This gives us the chance for a pause for reflection. I support the plea in the paper for the profession to contribute to the debate. Actuaries have tended to shy away from the whole subject of underwriting, let alone the philosophical considerations of Section 2. I encourage Mr Urmston and other senior actuaries in life assurance to involve their actuaries more in the underwriting process. There are things that we need to explore; for instance the pooling suggestions in Section 6.11. I believe that genetics will become a very regular part of medical diagnosis and treatment. I do not know when that will happen. What the profession needs to do is to contribute, and in many cases facilitate, the intellectual debate that will be required to take place in order to illuminate the emotional debate that is happening, and that will continue to happen.

Professor P. Donnelly, Hon. F.I.A. (Professor of Statistical Science, University of Oxford)**:** My current research work is in genetics, using mathematical models, modern statistics and computing, to complement the experimental work in understanding a range of issues, and in particular, the genetics of complex human diseases. The authors make a clear, and understandable, outline of the issues from an insurance perspective. The tension that they point to in the paper between the role, as it were, of hard mathematical analysis of well-posed models, and the range of public perceptions, and indeed public misconceptions, on the whole subject of modern genetics, is a very important one.

My comments concentrate on the perspective of the science and developments in the science, and how they might impact on two areas relevant to the paper. The first concerns public perceptions, and ways in which they may, or may not, change over time. The second concerns changes in the science, and how these may change the sorts of genetic tests that the authors, and those of you in the profession, will have to think about grappling with from an insurance perspective.

There is soon to be a very large project in this country, funded principally by the Medical Research Council and the Wellcome Trust, called the U.K. BioBank. The aim of this project is to collect information from about half a million people aged 45-70. The study will collect background information on environmental risk factors and exposures, on current health status, and also collect blood from which DNA will be taken for subsequent genetic analysis. The pilot projects will take place in the near future, with the project, as a whole, following from that. BioBank is bound to raise the public's perception of issues to do with genetics, and those of us involved in the project hope that that will happen in a positive way, as the public see potential health benefits and scientific benefits as the project evolves. It will also affect, one hopes positively, the level of public understanding of some of the genetic issues. Over time, that project and other research will bring successes that will touch people's lives in improved health care for themselves and their relatives.

The paper and several of those people who have taken part in the discussion pointed to the fact that, over time, genetic tests will probably become a much more routine part of our health care. As the paper notes, our current understanding is very limited to defining categories of diseases in terms of broad symptoms. What we expect is that many diseases can actually be stratified genetically. Genetic tests will then play a central role in the choice of therapies or intervention. Another impact will be in the growing field of pharmacogenomics. The basic idea there is that our responses to drugs are themselves genetically controlled. Some individuals will metabolise drugs more quickly than others, or in greater quantities than others. The side effects from drugs may have genetic predictors, and if, and when, we understand those better than we do currently, it is likely to be routine for us to have genetic tests before drug therapies are proposed and prescribed. Again, as that happens through time, one hopes that that positive impact will make genetics much more a part of people's lives. There might be a more positive outlook and may be less mystique.

I chair the scientific advisory board of a company called CODE Genetics, a genomics company based in Iceland. There has been an enormous public debate in Iceland over a project effectively involving the whole Icelandic population in genetic research. There are issues which have been controversial, both about the way in which that debate happened and the outcome, but there have also been many positives. That was a chance for a society as a whole, rather smaller than ours, to address the sorts of concerns that have been discussed, and to become more involved in decisions about what happened to the Icelandic gene pool and how it can, or cannot, be used for medical research.

The second issue is how changes in science might impact on some of the issues that we are talking about from the testing point of view. There is an enormous range of opinions about how quickly developments in the field will become everyday practice. The paper points out that many within the genetic field have over-hyped the subject. That is absolutely clear, as five or six years ago predictions about where we would be now implied more progress than we have actually made. On the other hand, one of the major players in the diagnostics market recently

announced that it anticipated that, over a few years, genetics-based diagnostics would be a multi-billion dollar industry.

The paper talks principally, and for very obvious reasons, about so-called sequence based, or DNA based, tests and diagnostics, the idea of checking each individual's DNA, their genetic make-up, to see whether they have this particular variant or that one, one of which may make them more less susceptible to various human diseases. In parallel with those developments there are other diagnostic techniques. There is a technique called gene expression analysis, which measures, not which genes you have, or which variants of genes you have, but rather which genetic products the body is producing, and this could have a major role in diagnostic tests. This technique could pose the same questions, or different questions, as existing sequence-based diagnostics. It is clear that people regard their own DNA, their genetic make-up, in a very fundamental way. They are much less worried about having their blood pressure tested or their cholesterol tested, and so on. Diagnostics based, not on DNA, but on the products of DNA, on gene expression, may fall somewhere between the two, and it will be interesting to see, as they come online, what effect they will have, and how the public will perceive them.

I now answer specifically the question raised about longevity. There is a strong genetic component to longevity in two senses. It is clearly good for someone not to have bad variants, variants that make you susceptible to common diseases. There is also growing evidence that there are good genes for longevity, independent of avoiding all the 'disease buses' under which one might fall. There are individuals with particular genetic make ups who are more prone to living longer. It is an exciting field in genetic science, and also has consequences more widely in the actuarial profession.

Professor D. Johns (a visitor; Chair, Genetics and Insurance Committee)**:** I took special note of ¶¶4.3.2 and 4.3.3, where the Genetics and Insurance Committee is referred to, in particular the views of Professor David Wilkie are taken account of in some of the modelling that was done.

If I have one doubt, as an engineer, in what I have seen in terms of the modelling, the question that I ask is: "Would I be happy with a model that did not have some continuity with other phenomena outside the particular range of activities that I am investigating at this time?" If I may just quote concerning some other points considered by Professor Wilkie: "These included the use of the normal distribution and the assumption that intensities of death depended only on durations since onset and not also on age." That is a very relevant point, because, if other models are built into the submissions made by the ABI to the Genetics and Insurance Committee for consideration, those are likely to give us some pause for discussion, and perhaps concern. If a model can be created which does not have such 'oddities' in it, then we will be happier in the work that we have to do.

The Genetics and Insurance Committee has a very precise set of terms of reference. We are not looking at the social and ethical issues. We are not the Human Genetics Commission, which does its own excellent work, and we benefit from its deliberations. We consider the issues or matters that they refer to us. We have had two meetings since we were recreated, and the debate so far has been mainly on the original criteria that we were set up with and whether they should be revamped. When we have finished our meeting next month we will probably have a revised set of criteria. It will then be for us to discuss with the ABI what they wish to do regarding the 18 applications which have already been submitted, and whether they would wish to revisit those in the light of the new criteria. I hope that we can find some way forward in terms of the actuarial models being used that did not raise questions of the kind that were raised previously.

The question of peer review has been raised, and whether the panel of experts which was used in the previous existence of the Genetics and Insurance Committee is a sufficiently robust method to make sure that the actuarial profession is happy with what is being done in its name in the submissions coming forward. That needs some debate. Who pays for such detailed peer review is a separate issue. The Genetics and Insurance Committee, as a Committee, has no separate funding, and I am not sure whether the Government would think that this should be

done by the insurance industry or whether the insurance industry thinks it should be paid for by the Government.

Reference was made by the last speaker to the issue of pharmacogenomics. The whole issue of human tissue being non-linear and variable makes me very humble, as an engineer, where so much of my work is based on materials which are linear and predictable and easily worked. When one sees what can happen in hospitals or in general practice when things go wrong, we must make sure that we have a system for working with health care professionals that gives them confidence that they can report what they are doing, if we are to get the better database to help us build better models for use in actuarial work. If a way can be found to make it easier for reporting to be done in a way that is useful, not only in terms of the building up of the models, but in terms of general information available for the treatment of various complaints and disorders, then everyone should gain.

Mr P. A. C. Seymour, F.I.A. (closing the discussion)**:** From the paper's reception it is clear that it has already made a significant contribution to the social policy debate at least, and I thank the authors for their excellent stimulus.

My association with the subject dates back to when actuaries formed their Health and Care Committee in 1993. At that time we recognised that we had to work with all sorts of other professionals. One of my early experiences was when we went to see Professor Roy Anderson, who is now an Honorary Fellow of the Institute, with the then Health and Care Committee Secretary, Mark Robinson. Last week the profession dedicated the ground floor meeting room here to Mark's memory, because he was killed in the latter part of last year on his way to work.

Professor Macdonald has been rightly praised by number of speakers for the work that he has done in this field. I recall his 1994 paper to the Faculty Student's Society entitled: 'The Death of the Life Table'. The opening section referred to 'tossers'. The thesis of this paper, which you will find echoed in what we have heard in this discussion, is that actuarial technology was thoroughly out of date; the 'tosser' reference was heads and tails, which is dead or alive. That was the technology that we were using. There is limited mathematics in this paper covering the use of multistate models. This illustrates the fact that we are improving our technology to meet some of these future challenges.

I remember, too, the first meeting that we had in 1996 with the Royal Society on genetics. Again, there has been reference made to that. It ultimately led to the formation of the U.K.FGI, that model being proposed again on a very multidisciplinary basis, following some work that the profession had been involved with in the field of continuing care.

The reason for trying to set the scene in this way is to convince the doubters that we, in the profession, are actually very keen to try to inform the debate as 'light not heat'. There has been quite a lot of heat. My impression now is that a lot of the 'heat' has gone out of the subject, at least in the context of insurance. A number of people have said that we must move on.

I have three headings for people's comments. The first is the question of fairness, the social policy question of solidarity versus mutuality. We heard that Australia is already deeply into this debate, but there they have their own divergences of opinion.

Mr Whittaker's contribution struck me, as his argument is about the reasonableness of underwriting decisions and not the science. I believe that we will never be able to be scientific about underwriting. Mr Turvey mentioned motor insurance, but this is very different. Flood insurance was mentioned, which is nearer. You can choose where you live, or you can sell the car, or whatever, but underwriting principles, as Mr Turvey said, are quite right. You apply for motor insurance and get whatever they quote you. Why should it not be the same, in principle at least, in this area, provided that we set up systems that enable some degree of solidarity or social policy to be injected into the structure of what we do?

Mr Thomas used some very thought provoking language, such as 'malign influence'. Accusing the profession of having had a malign influence is a little bit strong. This may be partly to do with the difference between the profession and the industry. The argument was adduced

similar to the AIDS argument, that if you want the results of tests for underwriting, people will be discouraged from having them. I agree with Mr Thomas in that we have gone beyond that now. I am hopeful that more of the light will appear and less of the heat. Further evocative language was 'hostile to human rights'. I do not agree, so long as we are prepared to understand that this is a matter of social policy, and that it is necessary for people to decide the balance, as Ms Martin called it. Then we had another Australian contribution from Mr Doble, and that was right back to the right to underwrite. I have every sympathy with that as well, but it shows how difficult this balancing act is.

Mr Kent, as Miss Morrison had earlier, focused on how it feels as a customer, which is very important, and is one of the areas in which we, as a profession, are now trying to make a positive contribution in terms of the education of financial consumers.

The second heading is technology. The opener made a contribution about multi-state modelling. I have already commented on the excellent work that we have done there. I was struck by Mr Kenna's comment, because there is reference to this in ¶6.4, about the behavioural aspects. You get this in consumer affairs as well. We might just take that point on board. Miss Morrison made the customer focus point, and stressed that statistics are not there. Then we had a very interesting preview from Professor Donnelly about what might become available in the statistical sense with which we could work. That is something to which we can look forward to continuing to contribute. Then we got back to the question about the credibility of our models, and clearly that is a technical point which we shall definitely need to work up a bit.

My third heading is: 'What do we do next?' That is a most difficult question. Some of the ideas were obviously in the area of longitudinal studies. I was pleased that enforced genetic tests do not seem to figure on anybody's agenda, despite the concerns of Miss Morrison. Mr Urmston and Mr Reynolds again emphasised this question, that we need to find a way of collecting the data, even if we do not use them. So, there were a few themes coming through about future work. The obvious point is that there is plenty yet to be done and, as a profession, with the byline 'making financial sense of the future', we are going to have our work cut out.

Mr C. D. Daykin, C.B., F.I.A., Hon. F.F.A. (replying)**:** The Genetics Group was established by the Social Policy Board to address social policy issues. We have to admit that actuaries are relatively inexperienced in social policy. Some people have implied that maybe we have not really got to the nub of the social policy issues, but in the end it depends where you are coming from as to what you see those issues to be. We have tried to take a middle line, and to take on board all the different aspects, and so it is good to have been criticised both by those who think that we have taken too much of an industry point of view and by those who think we have been soft in not taking an industry point view, because that reflects the fact that we have tried to steer a middle path.

One of the key areas that we ended up with in the paper is that this whole debate opens out into the area of a scientific basis for underwriting. The closer has referred to that. It is possible that this could be one of the outcomes of this debate; that there will be more demand for underwriting to be more scientifically based, although one can argue whether this will be possible in practice. We would also agree with Mr Nowell that one of the biggest impacts of all this, so far as actuaries and the insurance industry are concerned, may be on the longevity issue. We refer to that in ¶7.1, and we acknowledge that, if genetics has a significant effect on treatment, diagnosis and therapies, then the biggest impact on the insurance industry could well be simply that people live longer. That could be a significant problem for the pensions world generally.

I emphasise one of the conclusions that we have come to from our work in this area; that genetic test information is much less predictive than most people seem to expect. Knowing the result of a genetic test usually still leaves almost as much uncertainty about what is going to happen to that individual as not knowing the result of that test. We are talking only about shifts in distributions here, and in many cases the shift is not very significant, particularly as many aspects of genetic tests and genetic information depend, not just on one test and one gene, but on

lots of genes, on the interaction between the genetic effects, and on other things such as environment, lifestyle and diet.

So, although a huge amount of progress has been made in the science since Watson and Crick described the double helix structure of DNA about 50 years ago, which kick-started most of this recent scientific work in genetics, each new discovery is perhaps more noticeable for raising new questions than for providing conclusive answers. This is an expanding funnel of knowledge in terms of what we know in society about genetics. This is going to continue to be a very important and exciting science in the coming years, which is going to transform our attitudes to medicine, to therapy and to lifestyle in ways that we cannot really understand at this stage.

One aspect of this which has worried us is the undue focus on genetics. We have wondered why we are focusing on these issues solely in relation to people with genetic conditions. What about all the other people with disabilities who are precluded from getting insurance for various reasons? Why should genetics give people a higher profile in terms of their ability to raise public concerns about these issues? There are much wider issues that should be looked at.

We certainly want to emphasise the need for more research, so that the debate can continue on the basis of a wider platform of knowledge rather than on an exchange of prejudices unsupported by facts. We hope that a higher profile for actuarial research in this area may lead to the development of more useful information coming out on the genetic epidemiology side, which Professor Macdonald and others have identified as being a significant shortcoming. We also believe that it will be very important to continue research into the possibilities of pooling, and how that might be used as a mechanism in the future.

The President (Mr J. Goford, F.I.A.): I have just come back from India. We had an entertainment one evening, and the musician had done her research and said: "I understand that actuaries wipe the tears from the eyes of the afflicted and put the smile back on the face of the loved ones", which I thought was wonderful — better than 'making financial sense of the future'.

I picked up from the discussion some emphasis on the behavioural side. We had a lecture here a little while ago about behavioural finance from Mr Peter Clark and his Consumer Affairs Committee. We heard again here about behavioural responses to genetic testing. Actuaries could do well to review the behavioural effects of what we do with our clients and their customers.

It remains for me to express my thanks, and I am sure the thanks of all of us, to the authors, the opener and the closer and all those who participated in this discussion.

WRITTEN CONTRIBUTIONS

Professor R. Dingwall (Professor of Sociology, Insitute for the Study of Genetics, Biorisks and Society, University of Nottingham)**:** The paper is a valuable contribution, as far as it goes, but it still misses one of the most important points in the whole policy debate, namely a more detailed consideration of the likely scale of the impact at a population level. If we recognise that only a relatively small and affluent section of the population currently have personal insurance products of the kind that would be affected by genetic discrimination, the social policy issues fall into a rather different perspective. The widest holding of personal insurance is, I suspect, in the form of endowment-linked mortgages. It may be possible to argue for a human right to shelter, but it is hard to argue for this being funded in a particular way.

The impact on pensions and long-term care is potentially important, but its importance depends upon the balance between public and private provision, which the paper hints at in its discussion of solidarity and mutuality. There is a fundamental tension between the extent to which genetic knowledge probably favours solidarity arguments in welfare provision, because this is the only way to pool the risk of the natural lottery of gene distribution, and the desire of

governments to encourage mutuality through the privatisation of provision. As things stand, it may be hard to get excited about insurance discrimination, except as an attempt by the better-off to protect their privileges, if it merely involves a few people on the margins of affluence being priced out, which will probably be balanced by others being priced in. If we had a situation, as in the United States of America, where large numbers of people were potentially excluded from basic levels of health care and other welfare provision, with no public alternative, then discrimination would be an extremely serious issue, although probably one that would then call the reliance on private mutual provision into question.

Mr P. L. Duffett, F.I.A.: Under the current moratorium concerns and fears are recognised, but not addressed, as the industry focus is to carry on business successfully within the constraints. The profession serves both the industry and the public by becoming engaged in those concerns and fears. The danger is that erosion of confidence leads to erosion of the industry, limiting both the range of products offered and their availability.

The approach set out in Section 6.6, of examining the issues surrounding the possible range of products which could be offered, together with their availability, on the basis that any genetic information which is, or could be made available, is also available to the insurer, is sound. It deals with the widest and most up-to-date scenario, and therefore any restriction or modification which arises when considering the issues will be for a known reason rather than the carrying over of a previous restriction for which the reason may be unclear or outdated.

The application of social policy issues often involves consideration of quantum, and this, in turn, often influences where the balance is struck between mutuality and solidarity (including subsidy through tax, etc.). Clearly, the approach of Section 6.6 allows the greatest flexibility in meeting social policy objectives.

Policyholders do not believe that insurers have always made all the obligations, rights and risks enjoyed and borne by each party clear to them. In the past there has been at least some unhappiness over surrender values, anger over pension contracts and, more recently, resentment over how bonuses can be cut. The profession can help to illuminate these subjects so that the industry can move away from a position of mistrust by policyholders in the motives and actions of insurers and a belief by insurers that policyholders conceal the truth. New products could require policyholders to maintain a defined regime to become entitled to additional benefits in much the same way as requiring the insured life not to smoke. These products operate best in an environment of understanding and trust.

Mr R. G. Thomas, F.I.A.: There are a number of further points I wish to make, as follows:

Adverse Selection and Propitious Selection

The discussion of adverse selection in Section 2.4 takes an insurance industry perspective, not a social policy perspective. Like most actuaries, the authors implicitly assume that adverse selection is an unambiguously negative phenomenon; but this is an insurance company's commercial perspective. From a social policy perspective, adverse selection is a positive phenomenon in many markets, at least in its first order effects; it means that the right people, people with higher expected losses, tend to buy more insurance. Adverse selection becomes potentially a negative phenomenon only in its second order effects, that is if it reaches a degree which makes private insurance unviable.

The extent to which adverse selection may be seen as positive from a social policy viewpoint probably depends on the insurance market in question. For example, some people might regard a degree of adverse selection in life or health insurance as positive; but the same people might regard adverse selection in motor insurance as negative.

The paper also omits to mention *propitious selection* (Hemenway, 1992). This refers to the notion that purchase of insurance may sometimes be a complement, rather than a substitute, for other risk-avoiding measures. For example, people may self select to buy critical illness insurance or medical insurance because they are health-conscious, conscientious 'worriers'

(propitious selection), rather than because they have private knowledge of future illness (adverse selection). Hemenway (1992) discusses evidence for propitious selection.

In many markets, adverse selection may be a stronger influence than propitious selection. From a social policy viewpoint this is fortunate. If propitious selection were to dominate, this would mean that the wrong people (those least likely to suffer loss) were buying more insurance.

The very vocabulary used by actuaries when discussing this topic betrays a particular perspective or bias: 'adverse' selection in fact means *adverse to the insurer*. 'Self-selection' would be a better, more neutral terminology.

Freedom of Contract

Paragraph 5.5.3 (a) implies a commercial norm that 'private trading legal entities' are not obliged to transact any particular contract with any individual customer; but life insurers are wholesalers, and the suggested norm does not apply to wholesalers in many other financial markets. For example, market makers on the London Stock Exchange are obliged, during market hours, to transact in at least 'normal market size' with any customer. Where the customer wishes to deal immediately in larger size, the market maker will often offer a less favourable price, reflecting at least in part the possibility of asymmetric information. In contrast, in life insurance markets pricing schedules generally appear to be linear with respect to the sum assured; less favourable prices for transactions of larger size are not observed. This is surprising in the light of claims that asymmetric information is a material issue.

Attacks on Disadvantaged Groups

I said in the discussion that some of the profession's contributions to this subject had made me ashamed to be an actuary. To give one example, in July 1999 the Faculty and Institute of Actuaries issued a press release attacking people affected by genetic conditions for taking advantage of insurance companies. In promulgating these remarks, the Faculty and Institute of Actuaries offered no evidence that people with knowledge of their genetic condition were in fact acting in the manner alleged; or that it would be financially material to insurance companies if they did. The attack on people affected by genetic conditions appeared entirely gratuitous. This is the type of activity which makes me ashamed to be an actuary.

Also in July 1999, the profession issued a position statement commending the approach of the ABI at that time, and commending the GAIC process. I was critical of that statement at the time. I wrote to the Working Party and I wrote to the then President of the Institute. In 2000 the statement was nevertheless reissued, and I again wrote to the Working Party. However in 2001, after the HGC reported, the statement disappeared from the profession's website.

The GAIC Process

Paragraph 5.3.4 states that insurers and some of us as actuaries may have misjudged the GAIC process. I did not misjudge it. I wrote on many occasions to the Working Party voicing my criticisms of GAIC, and suggested that the profession should voice them.

Public Understanding

Paragraph 6.8.1 suggests that there is a lack of public understanding of genetics and insurance. As with any technical subject, it is true that some of the public is uninformed; but actuaries and insurers make a mistake in assuming that all their critics are uninformed, and that their views can be changed by so-called 'education'. The problem for the insurance industry is not that it is misunderstood by its critics, but rather that some of its critics understand it only too well.

I agree with ¶7.4 that an increasingly questioning public will demand evidence for other, non-genetic, underwriting practices; and also with the implication of ¶5.5.4, that in many cases such evidence may be hard to produce. This suggests that many underwriting practices may need to change.

Antipathy towards Human Rights Legislation

I also referred to the contrast between actuarial profession's antipathy towards human rights legislation and the wider social and legislative trend to promote such legislation, and the problems which this is likely to cause for the profession. This is discussed in greater detail in Thomas & Sharp (1998).

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