ABSTRACT OF THE DISCUSSION

HELD BY THE FACULTY OF ACTUARIES

The President (Mr T. M. Ross, O.B.E., F.F.A.): Before we discuss the paper, I should like to mention the two pre-meetings which were held in Glasgow and in Edinburgh. This is something which a number of younger members have suggested would, for appropriate papers, be a useful innovation to aid understanding. I hope that the result will be to encourage more members to make contributions at sessional meetings, which can be quite intimidating for the less experienced. Although the attendance at the meetings was not large, the feedback that I have had from the authors and those who attended, was that they were useful and enjoyable. I sense that the response was sufficiently encouraging for the Faculty to organise similar meetings on appropriate occasions in the future, when I hope that more members will feel encouraged to attend.

The subject of this paper is one of increasing importance and relevance to actuaries, one which I feel is migrating from discussions of matters which are really quite subjective and dominated by the ethical issues involved, to a stage where we can begin to use data constructively. I have no doubt that will take some considerable time. Therefore, it is timely that we have such a substantial paper to discuss.

Mr D. Paul, F.F.A. (introducing the paper)**:** The Faculty and the Institute have been represented on genetics and insurance matters by the Genetics Group, chaired by Mr Daykin, and under the wing, in recent years, of the Social Policy Board. The authors of this paper are members of that Group.

It is six years since genetics and insurance matters were aired at the Royal Society, with associated papers from Professor Wilkie, Professor Macdonald, Mr Le Grys and the current President, Mr Ross. This paper attempts to cover how the whole debate has developed since that airing at the Royal Society.

We first give a chronology of events, and I now run through a few of the highlights. The ABI code of practice in 1997 is where we pick up the story. There was the formation of the Genetics and Insurance Committee, the Committee's subsequent setting of criteria, and then, a bit later, its approval of the tests for Huntington's disease for life products, which took place in October 2000. Subsequent to that, the Human Genetics Commission and the Science and Technology Select Committee of the House of Commons made recommendations in the run-up to the May 2001 General Election. We leave the story, effectively, in the five-year moratorium which started in September 2001, as agreed between the ABI and the Government.

In the paper we try to go beyond the chronology and explore why events turned out as they did, and even, in some cases, whether matters might have been treated differently. This leads into the underlying social issues such as: solidarity versus mutuality as a basis for insurance; and the debate about whether risk classification constitutes fair or unfair discrimination. Also, the profession needs to question what level of evidence is reasonable against a backdrop of society pressing for transparency and non-discrimination, however that be defined.

So, the questions can go on beyond 2006:

— Should actuaries argue for change, and what is the evidence?
— Is the ban likely to continue, and become accepted as a norm?
— Should we, as actuaries, focus on proving vulnerability of the industry to the aggregate effect of a ban, which is something quite distinct from the GAIC criteria?
— Overall, will the pace of recent developments in genetics, and their impact on insurance, become a real threat?

Mr R. R. Ainslie, F.F.A. (opening the discussion)**:** This is an interesting, readable paper, which offers a springboard from which the profession can decide where to concentrate its efforts going forward.

When I read the paper, what really struck me was the lack of trust between many of the stakeholders, the people who have an interest in genetic testing and the future of that genetic science. Six years ago there were many people who were basically in entrenched positions, saying: "We want to defend our own perspective." Those people were insurers, geneticists and politicians, to the exclusion of all others who had an interest. Nobody seemed to be looking for a win-win solution. Everybody wanted to win, in case the other outcome was that they should lose. We know that trust is a very important aspect of the whole debate on genetics; and we know, as actuaries, and, more importantly, as employees of insurance companies, that the media and the public have a high level of distrust in us. At the Royal Society meeting these were fears expressed from the genetics community that what the insurance industry might do could damage their valuable work.

The most worrying angle, though, is how some politicians view insurance companies and what their attitude is towards genetics. There is a quote from the report of the Science Select Committee of the House of Commons that illustrates this. Concerning the Huntington's disease test, it says: "We recommend that the reformed GAIC re-examine the decision to approve the use of the Huntington's disease's genetic test produced by insurers with extensive peer review, both for the data supplied by insurers and its own decisions." That quote leapt out to me as an example of how much distrust there is of the insurance industry, our ability to process data and to process it fairly. Basically, they are saying: "We do not believe in your abilities."

The obvious push back that comes through from the paper is the lack of trust from the insurance industry that the political community will give us a fair hearing. I sense that when we hear politicians, it invariably feels to us like a one-way street, pushing financial costs onto the insurance industry. That is a slightly invidious position, because politicians may think: "The cost may not be astronomic, but it is okay for you to pay it." This ignores the fact that with-profits policyholders and members of pension schemes are those who own the businesses in question. So, the insurance industry is viewed as a soft target, but quite unfairly.

Another example of where I have a feeling that politicians are not giving a fair hearing was in the Select Committee. They were talking about the three insurers who decided to ignore the moratorium and completely ignore all genetic tests. The Select Committee's interpretation of that was: "Are these not three great insurance companies, and is not everyone else useless, or why are they not panicking?" A more favourable, and less conspiratorial, interpretation might be: "The market is working very well. This company is ignoring this information; and that company is not."

This is a backdrop. In the paper the authors welcome the setting up of the United Kingdom Forum for Genetics and Insurance. I would certainly be interested in their views as to how well it is addressing some of these trust issues.

Moving on to the state of genetic science, I would have liked the paper to have addressed in a bit more detail the views of geneticists. It is very hard, as a man in the street, to get a feeling for how the science is evolving. Reading newspapers, I get the impression of a big change from the kind of miracle cure articles that were in them a few years ago to being more measured, questioning the value of screening, identifying genetic science as being more useful for how to target individual treatment rather than as something more widespread. I get the sense that the medical profession is inviting debate. That is to be welcomed.

Now considering the cost to insurers, in one sense it is hard to understand what we are all getting excited about. It is clear that monogenetic conditions do pose an antiselection risk for us, but with the moratorium and, more importantly, with the extensive use of reinsurance, no individual companies are likely to be particularly hit by bad claims. The framework is there for addressing some of these issues.

I feel that the moratorium is unduly generous. £500,000 of life insurance cover represents more than 99% of all policies sold; £300,000 worth of critical illness cover exceeds that 97% - 98% of all policies sold.

The issue for life cover is multifactorial genetic conditions. Reading the paper, and from our own expectation, I can see no path that takes us, as an industry, in such a way that we can ever use the results of these multifactorial genetic tests.

I would be more concerned that, as a result of a push back, the insurance industry should change the way in which it goes about underwriting, perhaps gathering more evidence from other areas to compensate for the lack of some evidence, and moving towards the preferred lives model used in the United States of America. I think that that would be a most unfortunate outcome.

For insurers, though, I think that the big issue comes from critical illness, long-term care, income protection (where there is definite vulnerability), and even from the monogenetic conditions for which we already have tests. Small markets, developing markets, like long-term care, could be killed off if there is an inequality of information.

In Section 4 the authors discuss the GAIC process. It was both illuminating and worrying. I suspect that I am not the only reader of the paper who was astonished to read, in ¶4.3.4, that there is only one test for one type of life cover which has been approved, and that is for Huntington's disease. I had been labouring under the misapprehension that all the work that had been done had somehow been approved. It seems amazing to have made so little progress.

One interesting point is that, under current underwriting practice, if you have a family history of Huntington's disease, but no symptoms, and no genetic test result, and you are a 40-year old wanting to buy a ten-year term assurance policy, one company would ask that you be loaded at only plus 75%. In differential terms, this is less than the difference between non-smokers and smokers. The industry may already provide quite a good service for many people in these areas.

On the GAIC process, I was surprised that the authors feel, as they state in ¶5.4.2, that the moratorium offers flexibility going forward. My reading of GAIC is that it is as likely as not that we will have insurmountable obstacles put in front of change to the existing process. That is most worrying if family history becomes drawn into the whole debate.

I now consider the role of the profession. The point that the authors make in ¶5.3.1, about the direction of the debate not following the moral angle, is very pertinent. I feel that this is one where the profession should focus its fire. I can see much sense in the ABI taking the lead in assessing whether individual genetic tests should be used, but it seems to be a professional issue to consider the moral questions. The profession's response to the Human Genetics Advisory Committee paper said that the concept of social common good had not been debated as fully as it might have been. What constitutes the social common good is a political issue, and not, in the final analysis, the property of insurers, interest groups or actuaries.

The environment is fertile for this discussion. There is no bias from other parties. If you go to the Select Committee report, it acknowledges the concern of insurers about the risk of adverse selection, and accepts, as a principle, that commercial insurance companies should have access to the same information as applicants, but only if there are no adverse consequences for society as a whole.

Another angle comes from the Nuffield Council on Bioethics in its report on genetics and human behaviour, where it says that where insurance is linked to important public goods, it is not unreasonable to balance the cost to these individuals and to society against the cost to the insurance industry. It then adds: "However, one must balance another aspect of the public interest, namely the need to ensure that the cost of obtaining insurance is not rendered prohibitive."

The authors discuss alternative approaches in ¶6.9, and draw their conclusion in ¶7.3. Do they agree that the profession should be concentrating on trying to lay out the moral questions about the role of insurance in society?

Professor A. D. Wilkie, C.B.E., F.F.A., F.I.A.: This is a useful paper, which continues the profession's increasing involvement in this subject.

As noted in ¶5.1.2, I am a member of GAIC. I was appointed in January 2001. GAIC did

not meet between May 2001 and September 2002, which was not the fault of the members. We were advised by civil servants that we could not make any decisions in the run-up to an election. The election was postponed and did not take place until June 2001. Then, since the chairman had resigned in December 2000, we had to wait until a new chairman was appointed, which did not happen until July 2002, and because the initial term of office of the first members was expiring early in 2003, it was not until the new members were appointed before we met, which we did, eventually, in September 2002. Because we have a substantially new membership, one of our first tasks has been to reconsider the criteria for the approval of tests for insurance use. We have not yet completed our deliberations and found new wording, but it does seem likely that the 50% and 25% hurdles, which are described in ¶4.1.4, will be replaced or supplemented by a requirement that an adequate underwriting methodology and basis exists so as to allow appropriate premiums to be calculated. That is a significant change.

It would not be mandatory for insurers to apply such a premium basis, but it is intended that the use of this basis would be sufficient to justify any premiums if their amounts are called into question.

My view on this is that we should look at the wording of the regulations under the Disability Discrimination Act which allows insurers to discriminate against those who are disabled, provided that it is "based upon information (for example, actuarial or statistical data or a medical report) which is relevant to the assessment of the risk to be insured and is from a source on which it is reasonable to rely, and also is reasonable, having regard to the information relied upon and any other relevant factors."

That sort of wording from the regulations is a bit cumbersome, but it seems to me that it means that it must be based on reasonable evidence. I know that most people who are carriers of some genetic trait are not disabled in the sense of the Act, but it seems to me very odd that insurers are restricted in what they can do when a person is disabled, but are not so restricted when they consider that it is likely that a person would become disabled or at least have some medical problem that would justify an increased premium. Therefore, in my view, insurers should act in respect of all medical underwriting as if the Act applied, and use what I would call evidence-based underwriting. I hope that the insurers, through the ABI, can provide that evidence in such a way as to satisfy the new GAIC.

One application of GAIC has been approved, as noted in the paper. There are still 17 applications pending. Many of these were biased in favour of the applicants, so as to show that the hurdle of 50% extra mortality would be passed, but this had the effect of making the resulting premiums far too low for any reasonable underwriter to use. In my view this was unsatisfactory, and these applications would not meet GAIC's likely revised criteria.

There are other problems about many of the applications which, perhaps, can be attributed to the haste with which they were prepared. They do not cover all the relevant policy classes. Thus, they cover stand-alone critical illness, but not accelerated critical illness, which I understand is the bigger part of the market. They cover 26-week deferred income protection, but not other deferred periods. I do not think that this is good enough. They also appear to have been constructed so that the calculations can be done in a spreadsheet, usually using annual steps. This might just be all right for life assurance, but it does not work for income protection, with daily payments, and recovery rates which vary rapidly week by week. They also simplify the model unreasonably, so as to make the sums easier, but often this simplification has gone too far. The overall structure of the desirable models depends on the insurance required, but not really on the disease considered. However, the parameters of the model and some minor details depend greatly on the disease.

Figure D.1 is the model for income protection, which shows how complicated it is. The models for life insurance, critical illness and long-term care are rather simpler.

A model like this cannot be calculated practicably in a spreadsheet. It needs a proper programme; but the methodology is straightforward, very similar to the PHI model in *CMI Report No 12* (CMI, 1991) or the AIDS models constructed by the profession in the 1980s. One needs to use a sufficiently short step size to solve the relevant differential equations numerically.

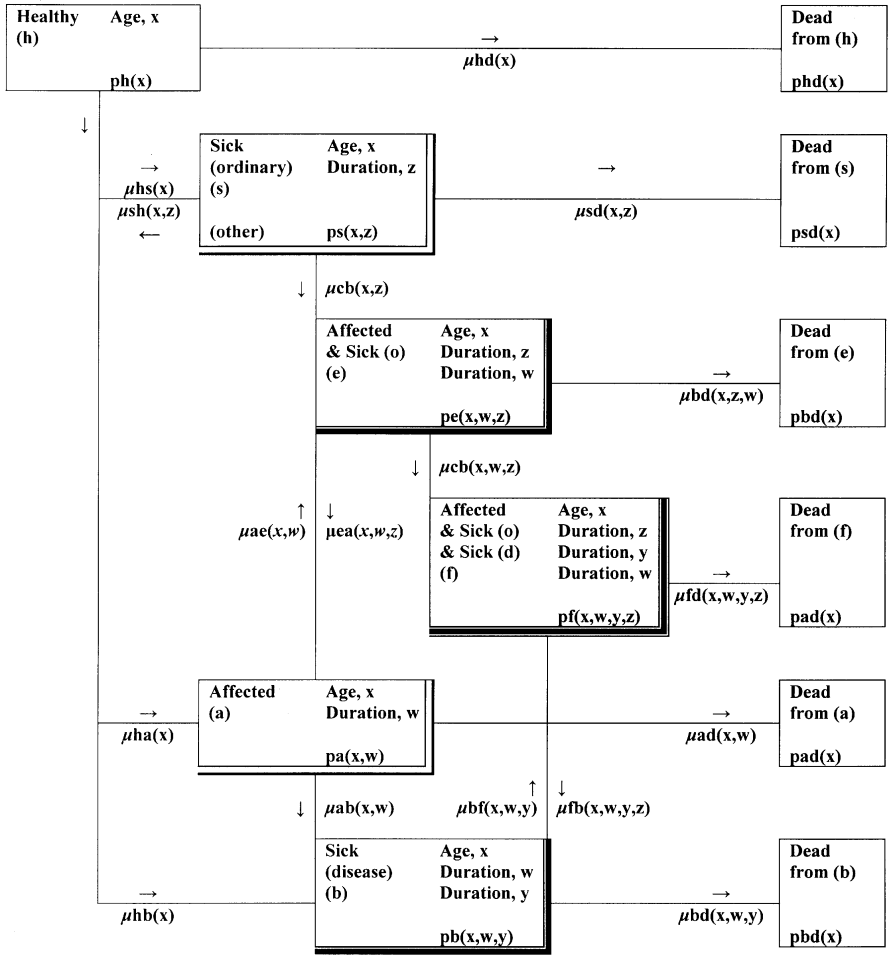

Figure D.1. Income protection model

Any method of solving differential equations should lead to the same numerical results. I hope to see future applications coming to GAIC using the right methodology.

Adverse selection is mentioned several times in the paper. It can mean either that someone gets insurance who would otherwise be declined or rated up, or that such a person effects more insurance than normal, because he sees it as a good bet or a good investment. I have seen no consideration of the rationale for this. In medical expenses insurance, for example, which is not much covered in the paper, one can only effect one unit of policy and not multiple units. In life assurance there is little incentive to effect a large policy if the chance of claiming is, say, 1 in 40, but the premium assumes a chance of 1 in 200. Your expectation is good, but you have 39 chances out of 40 of not claiming at all. One needs, to my mind, an odds-on bet or a near certainty before excessive insurance becomes a worthwhile investment.

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Pooling is discussed in Section 6.11. In my view it would be quite fair for the taxpayer to contribute to the costs of a pooling arrangement. The taxpayer contributes to the cost of genetic research, presumably on the grounds that this research will benefit society at large; but the existence of DNA testing may disadvantage some individuals financially. I do not see that it is right for society to pay to get the benefits of scientific research, but not to pay the cost of some relatively small adverse side-effects. A government contribution to a pooling arrangement is entirely justified. In fact, a reassurance pool for haemophiliacs infected with the HIV virus was suggested in 1987 by Dr Patricia Wilkie. It did not get off the ground, but the Government did make alternative money available to all those infected, which certainly helped them financially. I do not see why something similar in the case of people who are discovered to have adverse genetic traits might not work as well.

Professor J. A. Raeburn (a visitor)**:** I was the genetics adviser to the ABI from 1996 until the present time, and I was a member of the first GAIC from 1999 to 2001. I was asked to resign on account of a perceived conflict of interests.

I was quite anxious when I heard the details of the moratorium in September/November 2001, because my main interest in working at the interface between genetics, actuarial studies and underwriting had been that I saw that there was a chink of light which might give information about the risks that there were when you had certain genetic susceptibilities, and that this might lead to a social way to help them.

The menu that had been suggested by geneticists in the early 1990s was not something of which I approved. Broadly speaking, it appeared to be: "Let us ditch *uberrima fides* on behalf of the insurance companies, and let us allow those with a genetic disadvantage to benefit in some way or another." I could see, as a generalist as well as a geneticist, that there were many other needy groups, and that the genetic way had to be a pilot towards different ways of helping. After all, genetic illnesses are not common. That was one of the major reasons that my genetic colleagues gave for not using any genetic test results. They said that it was only with the rare single gene disorders where there was going to be a problem, and that these were epidemiologically so unusual that any insurance company could cover the possible loss.

However, I saw that small number as a possible opportunity for doing academic studies. I must compliment the Faculty and the Institute for bringing ideas together in an excellent document. Some of the findings of the Genetics and Insurance Research Unit are not only providing information which helps insurers to look at genetic risks, but is also contributing to a political arena, for example whether or not you might use a change within the Huntington's disease gene to predict the future age of onset rather than just interpreting a result as positive or negative. I can see the genetic epidemiologist of the future, perhaps completely unaware of the conflicts that have taken place over the last decade, saying: "Thank goodness that there is now really sound mathematical evidence on which I, as a geneticist, can pass on information to my patients."

One of the things that influenced my own involvement and sticking my head above the parapet rather too far was that I could not stomach sitting in a clinic, as I do three days a week, talking to people who have had a genetic test, and telling them the implications of that test to the best of my ability, and then sitting in 51 Gresham Street, or perhaps in the Department of Health, pretending that the data that I had just given to a patient are not relevant in the insurance context.

One of the great advantages that an actuary has is that he or she is not influenced by the state of the individual — of course you are at a subjective level — but is influenced by what happens to the group. I felt that actuarial evidence was going to help actuaries answer those questions, and that it would filter down to geneticists. If the mathematics did not bear out an expert risk assessment, then we would, as geneticists, have something to look at, and perhaps would have to change.

The comment that I should like to leave with the meeting is that perhaps now, as a result of the good work of the Faculty and of the Institute, and of the many people who are gathering

data and looking at new models, geneticists will benefit and will give more accurate information to patients in clinics. The social aspect of that could well be — and I totally agree with what Professor Wilkie has hinted at — that, if a person has a major disability on account of a genetic susceptibility, we can perhaps measure how much effect it has in the areas of life, critical illness, long-term care, or perhaps income protection insurance. Armed with that information, we can then look at what are the social goods that we, in a wealthy country, should use. I do not believe that the answer is to ignore the facts about risk. The answer is to identify the risk and to provide a possible subsidy. I certainly agree that it should be provided by government, even though I know from discussions within the ABI and from many colleagues from the insurance industry that members of the industry are certainly prepared to contribute.

Then benefits would flow down to the people who have a genetic disadvantage. People who are at risk of Huntington's disease or of Marfan's syndrome or of any of the many other, quite rare, conditions have clear ideas about what would help them physically: "Can I make sure that I get a wheelchair in ten years' time? I have seen my positive genetic test result. It is not going to influence my mortality, but I want to be mobile in five years' time, if the neuropathy should progress." Or the person with Huntington's disease as a positive genetic test, not yet affected by the condition, may say: "I want to provide some slight extra provision for my family because, over the years, a succession of people in my family have developed the disease in their fifties and therefore they have lost ten years of working life. That has had the obvious consequence upon my family."

If we were to try to help people who are as clear-thinking as that, what we should do is to gather the information and to ask those people with genetic disadvantages: "What is it that you would want?" They will, in turn, tell us a likely list of those social goods that could be provided. If we do that, we will actually find that the cost is probably even less than the cost that might be estimated from adverse selection in a number of circumstances. And so, from the industry's point of view, from the government's point of view, and, most of all, from the point of view of somebody who has a genetic disadvantage, we could be working together.

Mr J. G. Wallace, O.B.E., F.F.A.: I have read the paper with much interest, but I am concerned about the publicity aspect of this matter. I would state, however, that I am no longer associated with life assurance activities or with actuarial matters, so my comments can be treated largely as coming from an elderly (but not yet geriatric) member of the general public, and not as an actuary.

As an ordinary member of the public, until I read this paper I was unaware that there were a number of genetic committees deliberating on this subject. I was also unaware that there was a five-year moratorium and quite unaware of the reasons for it. That suggests that something is wrong with our publicity, because I have checked up with people in other financial fields and none of them has heard of this problem.

The initiative of the profession in 1998, in forming a broad discussion forum on genetics and insurance, is much to be welcomed. The resulting formation of the Genetics and Insurance Committee and the Human Genetics Commission are useful steps in promoting public awareness. These bodies are stated to have the dual task of educating themselves on the technical actuarial aspects of the problem, so that we can make use of the information when it becomes available; and also the broader and, in my view, more difficult issue of educating non-technical commentators and the general public on the philosophical issues which are so clearly set out in the paper. I do not think that there is any difficulty in continuing our research into the technical aspects of the problem, but how to deal with educating the general public on these philosophical issues is much less clear.

The publicity aspects of communicating the profession's views to the public deserves specific consideration. It is not only on genetic issues that publicity has been lacking. There are general issues such as: the lack of satisfaction on the use of with-profits policies for repaying house purchase mortgages at a time of falling interest rates and rising house values; the accountants' requirement that we have to show actuarial deficiencies in pension schemes analogous to

debentures in company accounts; and the lack of reserves for guaranteed annuity options. Such problems should also receive publicity consideration. I hope that the appropriate actuarial board will give consideration to this general problem, perhaps by facilitating meetings where the views of the profession on publicity can be aired.

On a minor point, I have had some association with these problems going back close on 60 years. When I came back from the war, I was pitchforked into dealing with underwriting problems in association with a distinguished senior consultant physician who was a disciple of Sir Robert Philip, the leading tuberculosis authority of his time. As a result, he took a somewhat severe attitude on tuberculosis cases, particularly if there was a family history of tuberculosis deaths. We used to underwrite these cases by using double endowments, decreasing debts, and so on. The magnitude of the extra risk was just guesswork. I remember studying certain American papers on the subject. The actuarial basis for the assessment was very flimsy indeed.

In their conclusions the authors suggest that the industry would be concerned at restrictions on the use of family history of deaths as an indicator of potential extra risk, particularly if it is so associated by future predictive genetic analysis. It seems to me that such a restriction would be somewhat difficult to enforce, because registered genealogical information about deaths and causes of deaths is publicly available, apart, perhaps, for some ethnic groups.

There is the possibility that there will be major and rapid progress in molecular research and genetic epidemiology. The public concern that a genetic superclass and a genetic underclass will emerge among lives assured is understandable. If there is this progress, would there not also be considerable pressure for a genetic superclass among genetically damaged annuitants? Judging from the information in this paper, a predictive situation such as this is not imminent. I strongly support consideration by the profession of the general publicity problem, which, in my view, should cover annuitants as well as lives assured.

Professor M. Steel (a visitor)**:** I follow on from that valid point on the need for publicity about the interaction between genetic disorders, susceptibility to disease, life assurance and other insurance underwriting matters.

The patients that Professor Raeburn and I see week in and week out at genetics clinics are not entirely representative of all those at risk of genetic disorders. We see, if you like, the activists, those that clinical psychologists call the 'monitors' (as distinct from the 'blunters', whose reaction to possible genetic susceptibility is to bury their heads in the sand). Therefore, the feedback that we get from patients is, perhaps, not totally representative; but even among the activists it is clear that there are misunderstandings and misapprehensions about the implications of genetic susceptibility for life assurance, annuities, and so on.

In something like 15 years, I can count on the fingers of one hand the numbers of patients who were seriously concerned primarily about the implications of a definitive genetic test. However, a number have become concerned that they were offered life assurance at special rates because of their family history. It is not widely appreciated that family history is a very legitimate concern of the underwriting profession.

The activities of academic actuaries in looking at this relationship between genetic susceptibility and risk and disadvantage in actuarial terms are extremely welcome. The take-home message that I transmit to my patients is essentially: "Don't panic." This is something that needs to be looked at carefully, and is being looked at carefully.

The function of the moratorium, again so far as my patients are concerned, is to remove a potential barrier to having a genetic test and to sharing the result of the genetic test with other family members. I doubt whether it ever has been the ultimate determinant of whether someone will or will not go forward for a genetic test. That must be unusual, but it is sometimes put forward as one issue in making what is often a difficult decision on whether or not to have a test. Furthermore, it can become an issue in deciding whether or not you will share that information with other members of your family, with your GP, and wider, because of the possible risk that the information will come back to be used against you. The advantage to the patient, to the family and to the medical profession of people undergoing these tests is, as Professor Raeburn

has said, that it allows you to ask sensible questions about the implications and to plan for the future. In the case of many families this is to plan for whether or not to have children, which then has an effect on the frequency of the disability in the population — seen most clearly in relation to Tays-Sachs disease in the Ashkenazy-Jewish community. It does not affect insurance underwriting, because this is a disease of children; but the frequency of the disease has declined dramatically because of the ability to recognise carriers, allowing the carriers to take reproductive decisions appropriately.

In the area of most interest to me, which is familial breast and ovarian cancer, it is now becoming clear that there are steps which can be taken to reduce the risk of death and the extent of morbidity from the disease if you know precisely who is at risk. It is expensive. It can be rather drastic in personal terms, and therefore is only justifiable if an individual is identified as being actually at risk, and known to carry the mutation. Therefore, you do not want to discourage people from taking these tests. Within the foreseeable future, I suspect that methods of reducing risk to known carriers of these mutations will become both practical, effective and relatively inexpensive. The moratorium is having a very beneficial effect in that respect. Other studies show that it is not hugely disadvantageous to the insurance profession. Therefore, I strongly endorse what Professor Raeburn has said about the need to work together to the mutual benefit of both the medical and the actuarial professions, and, particularly, to the families of those affected by genetic disorders.

Dr L. W. G. Tutt, F.F.A.: Naturally, the function of a profession such as ours requires proper involvement in purely commercial affairs, but how good it is to have a paper before us which includes in its title the words 'social issues', thereby reflecting actuarial interest in much wider and important matters which bear upon the advancement of society as a whole.

Indeed, the intensive research into mortality and morbidity rates carried out by the CMI Bureau and a number of individual actuaries constitutes a major contribution to social progress, and this paper demonstrates admirably the extensive sphere in which actuaries can assist in advancing understanding of life, so vital to human progress. However, primarily the paper directs attention to potential consequences for the insurance industry, and possibly may be regarded as suggesting a fundamental change in some actuarial outlooks.

To exemplify, the actuarial publication of 1998 entitled *Life, Death and Money* (Renn, 1998), stated, in its preface, that it was aimed at explaining how actuarial concepts contribute to social and financial developments, yet none of the authors gives anything other than the most scanty attention to mortality rates. Indeed, it is stated in page 42 of the book regarding mortality that: "Today, there is almost too much information." In fact, the emphasis throughout the book is that, in determining mortality assumptions as to the future, it is actuarial judgement which is necessary; see as examples pages 62, 113 and 207. Even in the recent paper by Haberman *et al.* (2003) to the Institute regarding decision making in defined benefit pension schemes, which valuably suggests an approach involving stochastic simulation, the authors indicate in ¶¶5.3.1.2 and 5.3.1.3 that it is common to assume that the demographic experience of the fund is deterministic.

Possibly relevant to all of this, the recent paper to the Staple Inn Actuarial Society, 'Mortality Improvements and the Cohort Effect', might seem to indicate, in ¶51, that actuarial judgement over the past 50 years has understated significantly future mortality improvements. Could this seeming misjudgement possibly have contributed to some of the problems being faced by the pensions industry at the present time?

In practice, it seems feasible that genetic information will not lead to a sudden overnight extensive improvement in mortality rates, but rather that increasing knowledge will result in the acceleration of past year-to-year improvements. This is a highly important factor for consideration by the life assurance and pensions industry, yet the possible extent of mortality improvements, even over the near future, seems highly speculative. Indeed, this paper is very largely of a conjectural nature, and perhaps the degree of speculation raised in it might hint that future mortality rates for adoption in life assurance and pensions calculations cannot be forecast with acceptable reliability.

Thus, could it be that the profession is faced with the stark fact that the two main bases on which life assurance and pensions business, as we understand them today, depend, namely future economic conditions affecting investment yields and future mortality rates, are largely indeterminate?

Doubtless actuaries will take exceptional care not to construct nor to maintain a highly elaborate edifice resting on a sandy subsoil, but this paper raises some fundamental questions for the future of the life assurance and pensions industry, and surely the statement in its final sentence that: "the actuarial profession would do well to address [them] well in advance of them becoming serious issues," needs very much to be stressed.

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Dr P. Wilkie (a visitor)**:** I am not an actuary, but I have a background both in social policy and in genetics research as a social scientist.

In the summer of 1972 I was offered a three-year research appointment, to be extended to five years, to test the acceptability of having a national genetic register, by the then Chief Medical Officer of Health, the late Sir John Brotherstone. The Scottish Office had already given a substantial grant to the then Professor of Human Genetics, Alan Emery, to test the feasibility of such a register, with the acronym of RAPID — Register for the Ascertainment and Prevention of Inherited Disease.

I went on to research further into, and write about, the social, psychological and ethical implications of genetic disease, and although I am no longer working directly in this area, I still lecture and am a reviewer on the subject for major medical journals and research organisations.

The findings of the acceptability study report in 1977, which we were not allowed to publicise, highlighted, among other matters:

— Whose information is this genetic information: the individual; the family; the unborn child; or society's?
— What about confidentiality of information?
— What about accuracy of genetic information that is kept about one?
— What about the ability of the individual to have his or her name removed from such records?
— What about confidentiality of the third party information, family members, and the use of genetic information and fear of discrimination by insurers, employers and educational establishments?
— What about the comprehension of risk by the general public?

I think that you will agree that we were possibly about 25 years ahead of our time, and so this paper is to be very much welcomed.

I now make a few general points and then some specific points. I do not know enough about how companies protect the confidentiality of applicants' records containing genetic information. Who within the company has access to this sensitive information? Is it restricted on a need-to-know basis? Can the applicants see the information that is kept about them to check its accuracy? It is only in the last few years, as many of you will know, that patients can have access to their medical notes. It is not always easy, and it costs up to £25 if you want a photocopy. However, I believe that you should have access to the medical information that companies keep

about you. Family history often involves giving information about third parties; that is, other family members who may not know that their names are held by the company. How can their confidence be kept?

Paragraph 1.2 is a minor point, but increased genetic knowledge *may* facilitate, not *will* facilitate, better treatment. While these advances may lead to an increase in life expectancy, they may also lead to an increase in morbidity, with an increase in cost to the individual, the family and health and social services.

In ¶1.4, I think that it would be helpful, when the paper is developed, if examples were given for the relatively common genetic mutations in certain small ethnic and geographically restricted communities. For example, carriers of sickle cell anaemia were restricted at one time to parts of Africa, but now have migrated all over the world. There is an assumption, in ¶1.6 and throughout the paper, that everyone will want to know about his or her genetic predisposition. A standard precondition for a screening test is that there should be effective treatment. Unless there is an improvement in treatment for genetic disorders, many may not wish to know that they have a predisposition for a very unpleasant illness which they may or may not get in the future, and for which there is no effective treatment.

I feel that there is a lack of clarity about the use of the words 'family history'. The taking of family history and the development of a family pedigree is an essential part of a medical genetic consultation. Before genetic testing became available the diagnosis for genetic disease was based almost entirely on family history and clinical examination, and for some diseases that may still be the case. These procedures may not give certainty. Is it therefore correct to say that family medical history information can be used as a proxy for genetic information? Family history may be genetic information. I believe that public policy should consider the responsibility that society has to those less fortunate than ourselves. If insurance companies are to be allowed to use genetic information, then the social consciousness of society should perhaps result in some sort of government underwriting of those at high risk.

In ¶2.2.1 there is an interesting discussion suggesting that behaviour can be affected by the presence of insurance cover, and with the suggestion in relation to personal medical expenses and income protection insurance. I cannot see quite how the behaviour of somebody with a genetic trait would be altered by having medical expenses insurance. Most genetic illnesses are chronic conditions, and in this country they are best treated by the NHS and, indeed, some private companies would not treat them. Genetic information is not quite the same as other predictive healthcare information. The public perception is likely to be that someone who has been treated for cancer, that is who has already had cancer, is not necessarily in the same position as someone who has been found to have a genetic predisposition to develop cancer which he or she may never develop. In one case we are looking at past facts; in the other case we are looking at probabilities for the future.

In ¶5.5.1 I was particularly pleased to see reference to Mr Jeremy Goford's comments on openness, transparency and accountability and evidence to support decisions. This is reflected in ¶7.4. Some three years ago the public were shocked to discover that the practice at Alder Hey Hospital in Liverpool of retaining organs without the knowledge or consent of relatives was widespread throughout the medical fraternity. This revelation has sadly resulted in a reduction in trust in the medical profession. It is hoped that this will not happen in the insurance industry, and that, perhaps, by demonstrating to the public that underwriting policies are based on rigorous scientific study that can be justified to applicants, this may help to reduce such loss of trust. This paper should help to prevent, I hope, an Alder Hey situation.

Professor D. Blackwood (a visitor)**:** As a psychiatrist, I have a direct interest in Huntington's disease through my work with patients in a Huntington's clinic, and also because of an interest in genetic research in psychiatry. It seems that the pace of clinical research in genetics is gathering momentum. There are going to be discoveries of genes for common complex disorders, and I think that the issues that we are discussing, which are set down in this paper, are a preparation for the fact that probably in the next few years there will be other examples

of severe illnesses that may be diagnosed before symptoms develop, about which people will want advice.

One example is depression. The World Health Organisation has proposed that depression will be one of the major causes of morbidity in 20 years' time. It affects around 5% of the world's population, and we may find the genetic basis for some types of depression. So these are important discussions, which may in the future be relevant to common diseases and not just a few relatively rare disorders.

Why do people want to be tested for Huntington's disease? It is important to look at the motivation of people and the reasons why patients seek testing. It is a terrible disorder for sufferers and carers. It starts between ages 30 to 50, beginning with memory loss and movement disorder. It progresses over ten years to a fatal outcome. It is 50% penetrant, and children have a 50% risk of inheriting the condition from an affected parent.

When testing was brought in in 1993 there were two major fears about how patients would react to the testing procedure. One major fear was that there would be a very high rate of suicide of patients given bad news after testing. Studies show that the suicide rate slightly increased, but fortunately it is a rare occurrence. However, the test can be very stressful. The other assumption that proved erroneous was the estimate of the number of people at risk who would seek testing. It was thought that about 75% of adults who were at 50% risk, and knew that they had this risk of illness, would seek the test. That was an over-estimate. The actual figure is about 10%, which is a very small percentage, considering that these are well-informed people who know the risk, but prefer not to know. The reason is simple; there is no cure for the illness. It is a minority view to want to plan one's life rationally by having a test and acting on the basis of odds. Most people do not behave in that way.

Why do people have the test? Probably the commonest reason is because they want to make decisions about having children. Some people want information because they prefer the certainty of proving whether or not they will develop the disease, but most people are 'ostriches', and prefer to live with uncertainty. Those who come for testing obviously want a negative test so that they can go back to their employers and be honest with them. They want to tell their boyfriend or girlfriend that they do not have the mutation, and they can go to life insurance and mortgage companies and get standard rates.

I think that the comment in the discussion about the importance of the motivation of people taking testing is very important. However, one thing is not very clear under the present guidelines. What happens if a person at 50% risk from Huntington's disease is tested and is told that they do not have the mutation, and then they apply for a mortgage? With the moratorium, can they present the genetic test result to the insurance company and say: "I have a positive family history of Huntington's disease, but I know that I am in clear; I have had the test." Even if the company cannot ask them directly for it, can they use the information? That is certainly something that people want to happen.

I go back to what Professor Raeburn was saying, in that it is very helpful for clinicians to be able to collaborate and to have information from the actuarial profession, because the issues that we are discussing are very important ones for patients.

Mr A. Doble, F.I.A., F.I.A.A. [Mr Doble submitted a written contribution to the discussion, and an edited version was read to the meeting. He also submitted the same contribution to the discussion held by the Institute of Actuaries, and the full version of his contribution appears in the abstract of that discussion on pages 840-842 of this part of *B.A.J.*]

Professor Steel: That was a very robust Antipodean point of view. It is predicated on the assumption that the medical profession, faced with the result of a genetic test, can then make a confident prediction about the outcome. That, I am afraid, is rarely the case. We need to gather much more information about the implications of any given genetic test before we are in a position to give sensible advice. Therefore, the advantage of the moratorium is that it does not discourage people from undergoing genetic testing. It gives us the opportunity to find out what

the implications are and what can be done about them. I think that you need that information before you can build it into actuarial practice.

Professor Raeburn: I pick up a couple of the points that Dr Wilkie mentioned for clarification in the discussion.

First, she asked how many people have access to the information. The ABI genetics code of practice did suggest that there were just three people who should have access to the test results or the family history reported to the insurance company. These would be: the company medical officer; the designated genetics underwriter, who was somebody who had had further instruction in genetics; and the genetic adviser. I am not aware of the monitoring of this particular aspect. The ABI is doing some other monitoring, but I think that that point needs attention.

The question about the assumptions which doctors make about the nature of people wanting to have a genetic test is very fair comment. This, in a way, is also a comment on Mr Doble's robust approach. I agree with an element of that, because I think that it will lead us into new areas which could also help people. However, we would be following the approach of the Advisory Committee on Genetic Testing for carrying out a genetic test. We do not assume that people wish for a genetic test. The information is passed to them by members of their family, rather than by a geneticist knocking at the door and saying: "By the way, do you know that there is a test?" If people wish to take it up, they can contact the genetic centre. So far as is possible, the confidential aspect and the personal viewpoint aspect are taken into account.

People have a right not to know if they do not want to know. I think that, in a more intellectual discussion of the insurance part, we need to find ways of asking a question in application forms which do not force people to know something that they would prefer not to know.

Mr G. Whittaker, F.I.A., F.I.A.A. [Mr Whittaker submitted a written contribution to the discussion, and an edited version was read to the meeting. He also submitted the same contribution to the discussion held by the Institute of Actuaries, and the full version of his contribution appears in the abstract of that discussion on pages 834-838 of this part of *B.A.J.*]

Mr S. P. A. Shearer, F.F.A. (closing the discussion)**:** We have had a very interesting discussion, although it was not that much of a debate until the Australians became involved.

I have come to this subject quite late, although I have kept an eye on it. My responsibilities did not cover this area until fairly recently. I have the impression that there was quite a degree of acrimony going on between the actuarial profession and the insurance industry on the one hand, and other parties, such as academics, doctors and politicians on the other hand. However, I thought that they were all coming closer together and that there was now less heat and more light being thrown on the debate. I think that this paper is a very valuable addition.

However, then we had the Australians coming in at the end and putting a very different point of view, pointing out that there is a very different way of addressing the issue, and that the way in which we are going within the U.K. is certainly not the only way, and is not necessarily the best way of looking at this subject. However, coming back to the discussion that we have just heard, I think that I was surprised at how long the debate had been going on. Again, I thought that it was a fairly recent event, but, as Mr Paul pointed out in his introduction, this has been going on for at least six years. Then Dr Wilkie pointed out that it had been going on much longer than that, but that it had come to be focused much more in the recent past. The comings and goings, and the to-ings and fro-ings, with committees being set up and then not meeting has obviously dragged things out rather longer than one would like.

The opener asked us a number of very interesting questions. He also reflected the view that there had been a lack of trust and that there had been a number of entrenched positions. Certainly I would accept that. The geneticists had, to some extent, created a rod for their own backs by allowing the impression to get out that genetics was another of these miracle cures that appear to come along every now and then. Clearly, as we see in the paper, and as we have

heard in the discussion, that is not the case. Genetic tests are a fairly imprecise instrument at the moment, although undoubtedly they will get better. They are precise in a number of very nasty conditions, but conditions which are fairly uncommon. So, the impact at the moment of genetic tests is actually quite small. The question is more: "Where will this go in the future, and to what extent do we need to set out our stall now to cope with the future?" which I think is the Australian approach, as opposed to going in the direction that we are, in the hope that greater collaboration will improve things for the greater good.

There was also discussion about mutuality and solidarity, and the issues about: "If there was to be any subsidy provided for the genetic underclass, who should that underclass be?" There was agreement, at least within this hall, that, if that was necessary, the subsidy should come from the taxpayer, through the government. It also seems to be the way in which our Australian colleagues are going.

Professor Wilkie gave us an insider's view of GAIC, and we also had other insiders' views. It is interesting to see just what had been going on, because, from the outside it appeared that very little had been happening. Also, there were some comments from Professor Wilkie and others as to just how likely adverse selection is in practice. Sitting inside an insurance company, it is obviously of great concern to us that adverse selection could materially affect the profitability of our business up to and including possibly making that business unsustainable. The view seems to be, at least in the short term, that adverse selection is actually quite unlikely, but clearly that could change over time as greater knowledge comes to be available.

We then had comments from Mr Wallace about the publicity aspect. I think that that was certainly a problem in the not-too-distant past. The insurance industry, as one of the other speakers said, is not the most highly regarded industry in our country at the moment. We have gone through a number of scandals, and we are not looked upon with great favour by the public and by politicians. This is an opportunity for us to redress at least part of that balance. Although I have some sympathy with the Australian approach, there may be a necessary tactical approach to try to win the public back while, of course, not throwing everything away, as I think that our Australian colleagues believe that we have already done.

Dr Tutt remarked on the fact that we had a paper in front of us with the words 'social issues' in the title, and that, perhaps, it was about time that the profession started thinking about the social policy aspects of our business. That is perhaps slightly, but not entirely, unfair. We have, perhaps, been rather too insular in the past. That is not really possible nowadays. We have only to open the *Financial Times* to read articles and letters from and about actuaries, so clearly we cannot hide from the world, as it might appear that we have in the past. However, I still think that it is very valuable that the profession is discussing social aspects and considering the impact on society of what we are doing and what our industry does. It is vital that we do take account of that.

We then had Dr Wilkie giving us a history lesson and asking us a number of very important questions, some of which were responded to. There is no doubt that there is genuine concern as to what will happen with this information, and it is important that information that is given to insurers in good faith is kept confidential and used only for the purposes for which it was intended. However, on the other hand, if that information is available to the proposers, then, under the principle of symmetry of information, it seems to me only fair that it should be made available to people who are taking on a financial risk as result of that information.

Then we came to the very robust points of view from Mr Doble. I think that we could paraphrase his remarks by saying that he thinks that we are a bunch of wimps and have given the game away. It was actually his colleague, Mr Whittaker, who expressed that in rather better language, pointing out the right to know, that it was not necessarily a level playing field, and that we needed to take account of that, going forward.

So, to sum up, there was a great deal of agreement within the hall that the research that is being done is very valuable research; that there has, in the past, been quite a measure of disagreement; but that such disagreement is becoming less. The profession and, in particular, the academic, but not exclusively the academic, part of the profession has worked very well with other

academics and other interested parties in working out what is really necessary, what is really practical, and what we really need to do. This action has advanced the cause quite dramatically.

We have a moratorium at the moment, and there is clearly an issue about how practical it is at the end of that moratorium to go back to something like more normal underwriting practices. I do not think that that is impossible, though clearly there are points of view which say that once you have given that game away you will never get it back. I think that what we have to do is to take the opportunity of that moratorium, where there is no possibility of discrimination, to do the research, to put forward the proposals, and then, it is to be hoped, in a few years' time, with much more reasoned debate, we will get back to a more normal state of affairs.

I leave you with a thought that I had myself when I was reading the paper. There is no doubt that the real benefits of genetic testing will be in the medical field. It will lead to better treatments and to a better prognosis for people with genetic diseases. To an extent, the insurance aspects, important though they are to everyone in this discussion, are a sideshow. What really matters is how well people are and how we can make them better.

How should the insurance industry and the actuarial profession step up to the challenge of not getting in the way of using genetic tests for the right things? If we think back to the AIDS scare about 15 years ago, the insurance industry very much ran away from term assurance and did not really contribute positively to the debate. They said: "We are just not interested in this, let us just leave it to other people to sort it out." Now, through a combination of safer practices and medical advances, AIDS is nothing like the problem that we thought that it was going to be. It may be that in 15 years we will look back and see that genetic testing is nothing like the problem that we thought it was going to be for the industry. Can we, as a profession and an industry, help rather than hinder?

Professor A. S. Macdonald, F.F.A. (replying)**:** I intend to pick up some of the interesting points that were raised by several of the speakers.

The opener referred to the role of the profession in the genetics debate, especially where it touches on social policy. He urged the profession to get more involved in questions of fairness and underwriting. It seems important that the profession has a voice in that debate, but its distinctive contribution, it seems to me, is the quantitative one. That came home to me quite strongly on hearing the comments from Professor Raeburn and Professor Steel that quantitative studies may even be found useful by geneticists in their practice. If that should be the case, then that is very welcome and very much to be encouraged. If, as Professor Steel said, it helps patients to be guided towards a rational basis for making very difficult decisions, then that would be a very positive contribution from the profession.

Another major issue that came up several times was that of trust. The depth of mistrust of the insurance industry in the U.K. is hard to overstate. The insurance company that may, today, be asking you about your family history or asking you whether you have had a genetic test, may be the same company that mis-sold you your pension in the 1990s, may be the same company which is sending you a projection for your endowment mortgage that is in the red zone, or it may be the same company that you remember turning down a friend in 1984 because that friend had just had a test for AIDS.

Overcoming that level of distrust is a very significant challenge. I get a strong impression that this distrust does not exist to the same extent in Australia. That creates a different working atmosphere between the actuarial profession, the insurance industry, the insurance regulators and other interested parties.

In terms of Mr Doble's comments, the question in Australia might very well be: "Why should genetic information be treated less simply than other underwriting information?" In the U.K. it is more likely to be: "Why are you getting away with rough and ready underwriting for non-genetics issues?" As Mr Whittaker recognised, that is the political reality in the U.K., and much of the paper reflects the road that the profession has perhaps been compelled to follow in order to try to restore a level of trust. Part of that, as Professor Wilkie said, is the extent to which we must convince people that we know what we are doing and that we are acting competently,

because we are constantly being asked the question: "How do you know?" If you say that the impact on the insurance industry of not having access to genetic information will be X, the question then comes straight back: "How do you know?" If you say that somebody who has a particular predisposition Y should be charged a premium Z you will be asked straightaway: "How do you know?"

In answering these questions and in trying to convince other professionals, such as geneticists and epidemiologists, that we do know what we are doing, then the kind of tools that we need are precisely those that are described in parts of the paper, as amplified by Professor Wilkie. What is necessary in the modelling process is, first of all, to write down a model that represents the problem as well as possible. Then you may find that you are able to use, or are forced to use, somewhat simpler sub-models because of inadequate data or because of difficult numerical computations, but that is a second stage. The first stage is to write down a model rather like the one which Professor Wilkie showed us.

The existence of, and the threat posed by, adverse selection were mentioned by several speakers. Professor Wilkie expressed the view that there is probably no incentive to over-insure significantly until the risk is almost a sure thing. This question is of interest to insurance economists, who would pose it in terms of the elasticity of demand for insurance. This is an area where there is a considerable theoretical literature in economics, but almost no empirical evidence whatsoever. It is another one of those holes in the research base that has to be addressed to convince bodies like the Human Genetics Commission that the insurance industry is presenting an accurate picture of the insurance world in the presence of genetic information.

An important question which was raised by the opener was: "Where is this pursuit of evidence going to stop?" It may have begun with genetic tests, but it quickly spread to family history of Mendelian disorders, from which it might spread to family history of complex common disorders. Where next? Professor Wilkie's suggestion was to treat all insurance applications as if the Disability Discrimination Act applied. I believe that that is already the guideline suggested by the ABI. Perhaps the significant change, though, is the GAIC process, because that has shifted the burden of proof from an occasional retrospective challenge in the courts, which is a very difficult and expensive thing to do, to prior research and prior establishment of the justification for an underwriting basis.

How do we educate the public, as Mr Wallace asked us? That certainly is high on the agenda of the Social Policy Board. I would not say that there is a lack of publicity. The trouble is that there is plenty of publicity, but all of the wrong kind. To the extent that we can help to move things away from there being both a deterministic view of what genetic information tells us and an almost deterministic interpretation of how insurers work, that will be of great benefit. In that context, I wish that we had seen Dr Wilkie's report back in 1977. That could have short-circuited quite a few of the machinations in the past six years.

Professor Blackwood asked how a negative test would be treated; that is, if someone had a strong family history, but nevertheless said: "I have had a test and it is negative." How will that person be treated under the moratorium? I think that the strict answer is that they would still be treated as if they had not been tested, and therefore treated on the basis of their family history. However, the real answer is that the insurance company would, formally, outwith the terms of the moratorium, almost certainly allow them the normal rates of premium for their other risk factors. This raises an interesting question. It seems obvious that this approach is a good thing — this is the insurance industry acting with the best possible intentions to spread the benefits of insurance cover at ordinary rates as widely as possible, and not letting the moratorium get in the way of that. However, if the message that comes back to the applicant is: "You have a family history of Huntington's disease, so we are going to reject your application, although we would accept someone like you who has a family history, but who can show us a negative test result", is that saying: "We want you to go and have a test before we will consider you as an insurable risk"? I think that there is a potential difficulty that has not been thought through, nor has there been enough experience yet within the industry to know how that will be presented on the front page of a tabloid newspaper.

The President (Mr T. M. Ross, O.B.E., F.F.A.): In drawing this meeting to a close, one impression that I will go away with, quite apart from the importance of the subject and the amount of work which has been done so far, is that it is still in its infancy. A great deal more thinking and work is needed. That said, I am very encouraged by the discussion and by the paper.

Our discussion was enriched by the contributions of several of our guests. It has come through loud and clear that, at a time of great uncertainty as to the immediate practical uses of many genetic tests, there is great potential public benefit to be gained from actuaries working closely with those in the medical field. Whilst, as actuaries, we are, of course, conscious of commercial implications, we should not rush to conclusions of what the commercial implications might be. Clearly, in the practical world there is a delicate balance to be drawn between the public interest and the commercial aspects. I thought that it was refreshing to see that balance emerging in the discussion.

We are very grateful to all of the authors for their paper, and I am sure that you would want me to encourage them to continue with their research. We look forward to another sessional meeting on genetics in the not too distant future.

WRITTEN CONTRIBUTION

The authors subsequently wrote: The wide-ranging discussions at both the Institute and the Faculty are indicative of the interest which our paper elicited. Since this is a topic which creates a lot of heat, it was no surprise that the views expressed were very diverse and that some speakers were critical of our stance — or of that of the actuarial profession. It was emphasised by several speakers, but perhaps needs to be said again, that the profession has no brief to speak for the insurance industry on this (or on any other) topic, and that we have deliberately sought to balance the interests of the many different stakeholders and not to take an industry view. Since the authors, as the members of the Genetics Group, are part of the structures which come under the Social Policy Board of the U.K. actuarial profession, we have also sought to discuss some social policy aspects of the problem, rather than focusing, as actuaries tend to do, on technical and financial aspects. Actuaries should be contributing to the debate on social policy issues — several speakers confirmed that this is also what they expect of the profession. Having said this, it is clear that the paper addresses only some of the issues, and is not a comprehensive statement of social policy in relation to insurance and genetics.

The most trenchant criticism came from fellow actuaries — from our colleagues in Australia, who thought that the U.K. profession had gone soft in being so willing to accept the concept of a moratorium, and from Mr Thomas, who considered that we had avoided discussing many of the social policy issues which he would regard as important. To some extent other speakers answered Mr Doble and Mr Whittaker. Clearly the situation in Australia differs from that in the U.K. In the U.K. environment the most plausible alternative to a moratorium would have been legislation banning the use of tests by insurance companies, rather than complete freedom for the insurance industry to use test results. The industry clearly deemed the moratorium route to be preferable, and we had no reason to defer from that point of view. A clear benefit, relative to the regulated environment which we see in many countries, is that there remains an incentive for research and for continuing dialogue.

Mr Doble thought that actuaries had overcomplicated the modelling process, and that the GAIC hurdle is both impractical and at odds with the approach used for underwriting other medical and non-medical risks. These two elements should be separated out. The modelling process which is being pursued in the context of recent actuarial academic research needs to be rigorous, and is entirely appropriate and necessary if it is to be published in peer-reviewed academic journals. We believe that such research will lay the foundations for understanding better the impact of genetic conditions on insurance contracts and the effect of adopting different underwriting approaches. The GAIC process, on the other hand, is driven more by political

considerations, and the requirements of the re-constituted GAIC have not been promulgated yet. However, the indications are that the GAIC may want to see the justification by the industry for the use of particular genetic tests achieving standards similar to those for research published in peer-reviewed journals. This, indeed, would be quite a heavy requirement for the industry, and certainly would be out of line with societal attitudes to underwriting more generally. However, this is the hoop which the industry will have to jump through, unless it throws in the towel and admits that it really is not worth all this effort to receive permission to make use of the results of a few tests, which will probably have very little importance for them anyway in the overall context of their business.

We strongly resist the assertion by Mr Thomas that the influence of the profession's statements in respect of genetics has been malign. As a profession, we have worked hard to take a line quite distinct from that of the insurance industry. Half of the authors do not have any direct connection with the insurance industry, and only one of the authors has any involvement in these issues from the perspective of a direct insurer, or took part in the work to support the industry submissions to the GAIC. Notwithstanding this, we do not believe that a statutory or a regulatory approach would be to anyone's benefit, and we support the current approach of a comprehensive moratorium. We were surprised at Mr Thomas's reaction to our suggestion that vulnerability should be demonstrated. Far from being a woolly concept, this would be an altogether tougher hurdle for the insurers to get over, as, in most cases, however clear-cut the interpretation of the genetic information, ignoring it will not matter to insurers from a financial perspective.

In his written contribution Mr Thomas argues that insurers are wholesalers. We do not agree. Insurers are manufacturers and retailers, and operate in a market which has a very different dynamic to the financial market-making to which he refers. Other things being equal, an insurer should be able to sell larger policies with a lower percentage mark-up, mainly because of expenses and commission, but larger policies are generally subject to more stringent underwriting so that the price can be matched more accurately to the risk. The authors strongly resist the idea that the profession has ever issued a press release attacking people affected by genetic conditions or that the U.K. actuarial profession has any antipathy towards human rights legislation. The reason that the position statement was removed from the website was because the Genetics Group decided to update it to embody material from the U.K. actuarial profession's submission to the Human Genetics Commission, and then concluded that it was not going to be possible to keep the position statement up-to-date as events were moving too fast, and that our energies should be directed, instead, towards developing a sessional meeting paper.

Some speakers questioned whether there would indeed be any possibility of 'returning to normal' after the moratorium. Probably not, but the period of the moratorium is still an excellent window of opportunity to increase our understanding of the impact of genetic conditions on insurance business and to encourage and facilitate dialogue between the stakeholders.

A number of speakers shared our concern that the high profile of the discussion about genetics and insurance — even to the extent of having its own government-established committee (GAIC) — may give undue weight to this particular issue. In many ways the response to the issue of genetics and insurance can be seen as having been disproportionate, but it reflects the particular concern which genetics issues raise in the popular psyche. Professor Donnelly questioned whether likely future developments in genetics, such as advances in gene expression analysis, would raise the same sort of concerns. The authors can only speculate on this, but our view is that all matters genetic will become less frightening to the general public as time goes on. The blurring of the edges between genetic information and the results of a whole series of other medical tests can only help in the process. We believe that there is a growing concern among geneticists that public expectations of the diagnostic value of genetic information have been over-inflated, fuelled to a significant extent by early hype from experts. However, most are now very much more cautious about what they claim for what genetic information will be able to offer.

Perhaps we should now be concentrating on the real challenges for social policy in relation to the insurance industry, which might include:

— how to find a socially acceptable balance between mutuality and solidarity which still permits a healthy and competitive private insurance industry to flourish;
— how to find socially acceptable ways of dealing with the problem of potential policyholders who are excluded by an insurance market based on mutuality;
— how to increase public confidence in the principles and practices of underwriting and the fairness and reasonableness of the 'discrimination' which it involves: and
— how the insurance industry can be more open in its dealings with the public, and be more accountable to society for its behaviour.

The actuarial profession has a part to play:

— through the influence of its members who work for or advise insurance companies;
— through the pursuit of relevant research by its academic members;
— through the encouragement by the profession of independent thinking which is sensitive to the interests and concerns of all stakeholders, and not unduly biased in favour of commercial interests in which some sections of the profession have a stake; and
— through the facilitation by the profession of dialogue between the diverse stakeholders on the basis of mutual respect, promulgation of good quality information and openness to the results of research.

One perception from outside the insurance industry is that insurance companies are large and wealthy institutions which can easily afford to absorb any losses resulting from a liberal approach to underwriting genetic conditions, or, more generally, from ignoring the information which they might have about policyholders' risk propensities. Sadly this is not necessarily the case, particularly when it comes on top of major shifts in financial markets and other problems affecting the industry. It is also the case for some of the insurance industry that it is other policyholders who will bear the strain, rather than the supposedly deep pockets of the shareholders.

However, insurance companies do need to be responsive to the pressures from the society in which they operate, and it is society which will determine the extent to which risks can be mutualised within the insurance company context, through the acceptance or otherwise of different tools for classifying risk. Curiously, there seems to be hardly any debate about the much more intrusive activities of building societies and banks in 'underwriting' mortgages, when they ask for all sorts of personal financial information, which might be thought to be just as sensitive for individuals, or perhaps even more so, than medical or genetic information.

In the U.K. we are where we are, with a moratorium which lasts until 2006 and a reconstituted GAIC which will re-evaluate the applications of the insurance industry to make use of genetic test results on the basis of its revised criteria. It is expected that the revised criteria will be more of a test for the insurance industry, and that the GAIC will seek to focus more on the relevance of test results for the actual underwriting and pricing decisions. The insurance industry needs to take seriously the concerns of society and politicians which have been expressed through the establishment of this process, and co-operate actively with it instead of trying to resist it. The actuarial profession has an important role to play in ensuring that those who make social policy do so in the light of good information about the possible consequences. For the actuarial profession, this should be a wake-up call to promote more actively an evidence-based approach to underwriting and premium rating.