

**The implications of genetic testing for life insurance / Human Genetics  
Advisory Commission ; foreword from Cairns Aitken.**

**Contributors**

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## THE IMPLICATIONS OF GENETIC TESTING FOR LIFE INSURANCE

### Foreword from Professor Cairns Aitken, Chairman HGAC Insurance Group

The Human Genetics Advisory Commission (HGAC) has been established as an independent group to take a broad overview of developments in human genetics and to report to both Industry and Health Ministers (see enclosed leaflet).

At its first meeting, the HGAC identified the issue of genetic testing for insurance as meriting early consideration, and formed a sub-group to explore the issue and its implications. This area had already been highlighted by the House of Commons Science & Technology Select Committee in its report "Human Genetics: The Science And Its Consequences" (1995).

The Insurance Group has focused on the Policy Statement about life insurance issued by the Association of British Insurers (ABI) in February 1997. The statement sets out a series of decisions made by the ABI's life insurance members, namely that for a period of two years:

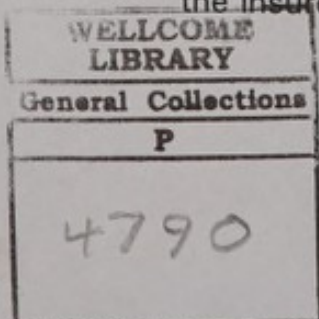
- its members will continue not to ask people to take genetic tests when applying for life insurance;
- for new applications for life insurance of up to a total of £100,000, which are directly linked to a new mortgage, the results of any genetic tests will not be taken into account by the insurance company. As at present, account will continue to be taken of family history and of other medical information;

- for new applications for other life insurance policies, individual companies will decide whether or not they wish to take account of the results of genetic tests previously taken.

The Insurance Group has also considered changes in policy adopted by some insurance companies which go beyond the ABI Guidelines. The Group is consulting with interested parties before reporting back to the HGAC in September. The Group recognises that the ABI intends to keep its policy under review and that the present statement may be amended or developed in the future.

The potential impact of genetic testing on the availability of life insurance cover in the UK has attracted a great deal of interest. There is concern that individuals who reveal the results of a genetic test to an insurance company may run the risk of being unfairly discriminated against, and either being refused cover or asked to pay a disproportionately high premium. An additional concern is that, if insurance companies insist on the declaration of the results of genetic tests, this may deter people from taking tests which might otherwise be beneficial. Concern has also been expressed that insurers might not have the relevant expertise to deal with the implications of genetic test results and might not yet have suitable rules for estimating risks or interpreting genetic information.

From the insurers' perspective, there is concern about "adverse selection", whereby individuals with "bad prospects" may be more likely to seek to insure themselves for larger amounts. This might, it is claimed, distort the fundamental basis of insurance which depends on spreading risks and subvert the doctrine "utmost good faith" between the insurer and the insured.





The Insurance Group is aware that some major life insurance companies do not subscribe to the ABI Policy and would be interested to hear from those companies as to how they arrived at a different position.

A discussion meeting held under the auspices of the Institute of Actuaries and the Royal Society in September 1996 concluded that genetic testing would have a bigger impact on medical, critical illness and long-term care insurance policies than on life insurance. The HGAC will be considering the implications of genetics for these other types of insurance and would welcome preliminary observations about any aspects that are of concern.

The Insurance Group is continuing to meet with experts while this consultation proceeds and your response to the attached paper would assist it in developing the Commission's view on the implications of genetic testing for life insurance.

Please send your responses by **10 September** to:

Ms Mileva Novkovic  
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Further copies of this document are available on request from Chris Hepworth (faxed requests preferred). Fax: 0171 271 2028 Tel: 0171 271 2064.

## Rationale for focusing on life insurance

A genetic test is a test to detect the presence or absence of, or change in, a particular gene or chromosome. Life insurance and health insurance are the two forms of insurance to which genetic testing is most relevant. Their relative importance varies between different societies. In the UK, where only a minority of individuals currently depend on private health insurance, it is less important than in countries such as the USA where it is the principal means of paying for health care.

For people in the UK, life insurance is often linked to home purchase and the covering of basic family needs. Therefore, it is of importance to individuals that they are not excluded from life insurance. It is to this form of insurance that genetic testing in the UK currently has most relevance. The implications of genetic testing for life insurance have attracted the attention of the media, the public and the insurance industry. This document focuses on life insurance but recognises that should dependence in the UK on other forms of insurance increase there are also implications for private health insurance, especially long-term care for the elderly or disabled.

We would be very interested to hear your views on the following questions or any other relevant matters.

### **1. Genetic tests - what are they capable of revealing?**

- a) The predictive capability of genetic tests varies and is likely to be even lower for multifactorial conditions than for monogenic disorders. How can you therefore ensure that genetic information



does not lead to a denial of coverage for individuals who may never get the disorder or may only become symptomatic many years in the future?

**2. What information about genetic test results is collected by insurers and how is it interpreted?**

a) How can granting life insurance on standard terms to 95 per cent of applicants be compatible with individual underwriting of risk?

b) What range of increased mortality risks do you consider acceptable for inclusion within the 95 per cent of standard-rated policies?

c) To what extent and on what basis do you take non-familial, personal predictors of risk into account when deciding to grant a policy? (for example, cholesterol tests, blood pressure etc.)

d) How do you arrive at a decision as to the relative importance of risk factors and predictors of risk?

e) Why are you interested in genetic risk predictors?

f) How do you quantify genetic risks and rank them with other predictors?

g) What medical/personal information about applicants do you routinely request? Do you ask about lifestyle issues e.g.

smoking, alcohol, dietary habits, exercise patterns, hazardous sports or occupations?

- h) Does this vary between different types of life policy and/or for different amounts of cover?
- i) What questions, if any do you routinely ask about applicants' relatives?
- j) How do you use individual information when assigning/loading premiums to the stated 5 per cent of applicants where standard terms are not granted? Similarly, how do you use family information?
- k) Do you currently ask, or plan to ask, any questions about genetic tests taken by applicants. If so, what questions do you ask (of the individual or the doctor) and how do you act upon the responses? Kindly give anonymised details of the types of applicants where you have asked such questions.
- l) Do you currently ask or plan to ask any applicants to undergo any genetic tests? If so, in what circumstances, and how do you act upon the results? Kindly give anonymised details of the types of applicants where you have asked such questions.
- m) Do you intend to ask about carrier tests for recessive conditions (where carriers are unaffected)? If not, is it clear to the applicant that their carrier status need not be divulged?
- n) Some genetic predispositions can be detected by either a biochemical test or direct DNA analysis. Would you make any

distinction between the method of testing used when considering the result?

- o) Given the concern that individuals may be inhibited from undertaking genetic tests for fear of being refused life insurance, in what circumstances do insurance companies contact applicants' medical practitioners? How do you think genetic testing might affect the doctor/patient relationship?
- p) On whom do insurers rely for the specialist scientific assessment of genetic tests?
- q) Are all decisions on loading or refusing policies based on risk calculations done in-house, or are they undertaken by re-insurance companies?
- r) On what basis was the figure of £100,000 determined as the ceiling for the sum assured which will not result in genetic tests being taken into account and why is this arrangement restricted to life insurance policies linked to a new mortgage?
- s) Where is £100,000 on the distribution curve of the number of mortgage applications against value of mortgages?

### **3. Research evidence**

- a) What access do underwriters have to relevant academic (actuarial or genetic) research results? Is the effectiveness of underwriting decisions audited?



- b) How do you define relevant? What would the prudent underwriter wish to know?
- c) What and how is actuarial research undertaken in this subject, where is it undertaken and who undertakes it?
- d) What data are used to construct actuarial tables for UK insurance applicants? How often are they updated to include new research, particularly research on rare genetic disorders?
- e) Do insurers fund actuarial research? If so, is this internal to the company or external in universities or other research establishments?
- f) How does actuarial research make use of epidemiological research? What use is made of data relating to morbidity/disability as well as mortality?
- g) What suggestions are there for improving knowledge about the relevance of genetic information and life insurance?
- h) Given that most clients outlive policies, what is the insurance industry's outcome data based on?
- i) How would you demonstrate that underwriting decisions are 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 as cited in the Disability Discrimination Act 1995 (Services and Premises Regulations 1996)?

#### **4. Confidentiality/security of information**

- a) How is medical information provided by an applicant handled and stored throughout the processing of an application?
- b) In particular, what information is transferred to computer?
- c) What medical information on databases is shared by a group of companies?
- d) What happens to this medical information, whether stored on computer or not, when an application is turned down by either a company or an applicant?
- e) What currently happens when a policy expires or is terminated for whatever reason?
- f) Would clinical information obtained for the purposes of a specific application be re-used to help assess another application (a further application from the same individual or an application from another person)?
- g) How are fire walls of confidentiality maintained between records of family members ?
- h) The ABI Policy Statement refers to the intention to collate statistics on applicants for life insurance who have had a genetic test. What information is intended to be collated and by whom? What will happen to this information? Is the fact that the information is to be collated for statistical purposes made known to the applicant

who completes the application form? What information about data handling is actually provided to the customer?

- i) The ABI Policy Statement also states that although results of genetic tests must be provided, they will not be taken into account under the specified circumstances. How will insurers demonstrate that the genetic information thus provided is not being used?
- j) What are the effects of the Data Protection Act (1984) on the life/health insurance industry? Does it pose any particular difficulties? Since the Act requires data not to be collected if it is not used, how can the current ABI proposals be justified?

## 5. Openness

- a) Do insurers have any general standards on e.g. feedback to applicants, customers' charters etc.
- b) What information/advice do companies give now to those refused cover or those whose premiums are loaded? Is it made clear where premiums have been loaded ?
- c) On what basis can those refused insurance or those whose premiums are increased decide whether to appeal against the decision?
- d) What information on the calculation of such loadings is made available for public discussion? If none, how does that square with "utmost good faith"?



e) How do appeals mechanisms operate? What evidence is there that they are independent of both parties with an interest?

f) How will the consumer know which company takes genetic testing into account?

**6. How is genetic testing affecting the insurance industry and how might it affect it in the future?**

a) Does the insurance industry have figures on the extent of "adverse selection" by those who have high blood cholesterol or high blood pressure, are obese, smoke or those whose socio-economic circumstances are poor?

b) Does the insurance industry have evidence that genetic "adverse selection" will have a greater impact than any of the factors listed in 6(a) above?

c) How is industry coping with the current availability of "Over the Counter" blood pressure and cholesterol tests?

d) How might industry cope if "Over the Counter" genetic tests become widely available?

e) Is there evidence that "adverse selection" takes place and that it will take place to a greater extent? e.g. what evidence is there that "adverse selection" occurred at the time of the previous "scare" on HIV/AIDS in the 1980s?

f) What financial analysis has been done by the insurance industry or others on the impact of "adverse selection" in the light of developments in genetics?

g) What procedures are in place or planned for screening applications for unusual buying practices?

h) Do you think regulation in this area might be helpful?

7. **"Cherry picking"**

a) What is the financial and corporate strategy which has led insurers to eschew cherry picking (or individual underwriting) in life insurance?

b) Is there a difference, other than form of words, between "cherry picking" and "underwriting according to individual risk"?

c) If it is a matter of collective industry decision to go for 95 per cent rather than for preferred lives, then what financial pressures do companies foresee that might drive them down the "cherry picking" route?

d) What characteristics would a genetic profile need to have in order to warrant a discount?

e) Do life insurers consider they would be interested in offering "preferred lives" ratings based upon genetic information, given the importance of lifestyles?

f) Do life insurers consider they would be interested in offering "preferred lives" ratings based upon "lifestyle" and environment?

**We are grateful to you for having considered these questions. If there is any other information you would like to give, please write to:**

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# Human Genetics Advisory Commission

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9 July 1997

Dear Colleague

## THE IMPLICATIONS OF GENETIC TESTING FOR LIFE INSURANCE

As you may know, the Human Genetics Advisory Commission (HGAC) identified genetic testing and insurance as an issue for early consideration. A working group of the Commission, chaired by Professor Cairns Aitken, has been exploring the issue having regard to the 1997 Policy Statement issued by the Association of British Insurers (ABI). The HGAC intends to offer published advice to Ministers by the end of the year.

The implications of genetic testing for insurance are complex. The ABI's statement is a useful starting point and we are aware that the ABI is talking to geneticists as it continues to develop its policy.

While we continue to meet with experts in the field, we are keen to learn more about how the insurance industry operates. To help us develop our thinking, the attached paper raises a number of questions directed to the industry.

The aim of this consultation is to find a way forward which is acceptable both to industry and to the population at large. For this reason, the Advisory Commission would welcome opinions from a broader section of society and I invite all those who have an interest in the use of genetic tests in insurance to come forward and share their views with us.

Accordingly, I would be very grateful if you could consider the questions in the attached paper. We would welcome responses by 10th September. Please reply to Mileva Novkovic at the above address.

*Yours sincerely,*

*Colin Campbell*

Sir Colin Campbell  
Chairman

