

The use of genetic information in insurance: Interim recommendations of the Human Genetics Commission

At the request of Ministers, the Human Genetics Commission (HGC) has been reviewing the wider social and ethical implications of the use of genetic information in insurance. As part of the ongoing review, the HGC met on 1 May to consider consultation responses, additional information from the insurance industry and the report of the House of Commons Science and Technology Committee.

The HGC concluded that it was important to establish a clear and defensible regulatory system which not only balances the interests of insurers, insured persons, and the broader community but also enjoys the confidence of the public. In order to achieve this aim, the HGC has therefore decided to recommend to Government an immediate moratorium on the use by insurance companies of the results of genetic tests. We note that the industry has accepted that genetic tests of any real predictive value are only relevant in relation to a very few rare diseases and agree that to exclude their use would have no serious economic impact on the insurance industry.

In the HGC's view the moratorium should embrace the following features:

No insurance company should require disclosure of adverse results of any genetic tests, or use such results in determining the availability or terms of all classes of insurance.

The moratorium should last for a period of not less than three years. This will allow time for a full review of regulatory options and afford the opportunity to collect data which is not currently available. The moratorium should continue if the issues have not been resolved satisfactorily within this period.

The moratorium will not affect the current ability of insurance companies to take into account favourable results of any genetic test result which the applicant has chosen to disclose.

The issue of family history information presents particular difficulties. The Commission is concerned that the insurance industry's principle of open disclosure and utmost good faith by the parties seems to fall most heavily on the consumer. Few people are provided with information as to how their premiums are loaded. HGC understands that family history information can amount to genetic information and is not always interpreted appropriately in underwriting. During the moratorium period HGC will address the issue as to how family history information is used by insurers.

An exception should be made for policies greater than £500,000. This will address concerns about adverse selection, the process by which persons having a known risk set out to acquire substantial insurance cover. (The HGC, however, has yet to see evidence of the extent to which adverse selection takes place in this context.) We recommend this upper financial

limit on the basis of the industry's own tables and information as a protection from significant financial loss.

Only genetic tests approved by the Genetics and Insurance Committee (GAIC) should be taken into account for these high-value policies. The HGC believes that there remains a need for an expert body of this kind, but that the criticisms of the GAIC voiced by the House of Commons Science and Technology Select Committee must be addressed.

In view of the failings of the current system of self-regulation of the insurance industry a method of independent enforcement of this moratorium will be needed. The HGC believes that legislation will be necessary to achieve this.

During the moratorium period, the HGC will continue with its consideration of the wider issues and should work with other bodies to identify a system which enjoys public confidence and the confidence of the insurance industry. An appropriate recommendation could then be made to the Government which could replace the moratorium with new arrangements.

Background to the decision

The current public debate in the United Kingdom on the use of genetic information in insurance may be traced back to reports of the House of Commons Science and Technology Committee in 1995 and the Human Genetics Advisory Committee in 1997. This latter committee, which was a predecessor body of the Human Genetics Commission, suggested that there should be a two year moratorium in the insurance industry's practice of taking genetic test results into account in deciding whether or not to provide insurance cover to a particular applicant, or deciding the terms of such cover. This recommendation was not accepted, and agreement was reached on a system of voluntary regulation based largely on proposals put forward by the Association of British Insurers. As part of this system, the Government set up the Genetics and Insurance Committee (GAIC) and the Association of British Insurers published a Code of Conduct, which was intended to be observed by all members of the Association.

The aim of this system is twofold. Firstly, it is designed to prevent insurers from requiring applicants to take genetic tests. Secondly, it sets out to ensure that insurance companies do not give to any particular genetic test a weight which it does not deserve. If an applicant has already undergone such a test, then he or she is bound to make that fact known to the insurance company before insurance cover is agreed. This is in accordance with the well-established principle of "utmost good faith" that an applicant for insurance should make known to the insurance company all those facts which are relevant to the underwriting decision. However, insurance companies should pay attention only to those tests which have been considered by the GAIC and are scientifically reliable and are capable of yielding relevant information.

In theory, this policy should provide both reassurance for the public and protection from arbitrary and unjustifiable decisions. In practice, there is reason to believe that the system is not achieving these objectives.

The House of Commons Committee on Science and Technology has recently published a report entitled "Genetics and Insurance". The Committee took both oral and written evidence from a range of persons and bodies, including representatives of the Association of British Insurers, individual insurance companies, and clinical geneticists. The House of Commons report admirably sets out a number of concerns, the overall conclusion was that the current system was not working well.

The HGC is also aware of these and other concerns from its preliminary analysis of the response to its public consultation. In November 2000 the Human Genetics Commission launched its consultation document on personal genetic information, *Whose hand on your genes?* One of the issues which was raised in this document was that of genetics and insurance, and the public was invited to respond to a number of questions on this matter.

This attracted responses relating to insurance from about 50 organizations. These included those bodies which have a close interest in the subject – such as the Faculty and Institute of Actuaries and the Association of British Insurers – in addition to a wide range of charities, unions, and medical royal colleges. A number of individuals also made submissions. As might be expected, many contrasting views were expressed, but it is nonetheless possible to identify certain concerns which are repeatedly expressed in the responses.

The HGC is not yet in a position to make detailed comment on public attitudes to this question, but it now has a body of evidence which suggests that there is a fairly strong public opposition to the use of genetic test results by insurance companies. This is revealed in the major MORI public opinion survey undertaken by the HGC and published in March 2001. It is also revealed in the majority of the responses received from individuals and organisations. The HGC has therefore concluded that the level of public concern over this issue requires a response. It is not suggested, of course, that strongly expressed press or public demands should dictate the precise form of any recommendation which we might make; all that is suggested at this stage is that we cannot ignore the widely-held view that the current system is unsatisfactory.

The HGC has now decided to recommend a selective moratorium on the use by insurance companies of the results of genetic tests. This decision is reached for the following reasons:

Regulation

The current system is not achieving the objectives which were envisaged when it was created. The most cogent recent criticism of it is that expressed by the House of Commons Committee on Science and Technology, which concluded that individual insurance companies were not equally observing the ABI Code of Practice, that they were using genetic tests that had not been approved by GAIC, and that currently there seemed to be no satisfactory means of monitoring and enforcing the Code. The HGC agrees with this assessment of the situation.

Genetic Tests

There remains a great deal of uncertainty about the interpretation of many genetic tests. The significance to be attributed to many tests is still a matter of debate, and this issue needs to be further clarified. It is likely that a clearer understanding of the possibilities

and limitations of genetic testing will evolve, but at present it seems undesirable to apply a technology which is disputed.

Social Exclusion

There are strong reasons for some effective form of regulation in this area, whether regulation is achieved by the insurance industry itself, or by more formal means. These reasons include the need to ensure that those who are affected by genetic conditions should not feel excluded from the normal benefits of society (employment, participation in public life, and, it might be argued, access to insurance). Over recent decades, the position of those with a disability has been steadily improved by legislation designed to enhance their opportunities in society. It would run counter to this commitment were society to allow new classes of persons to grow up which would be subjected to improper discrimination.

Individual and public health

Closely related to this consideration is the factor of public trust in genetic testing. If people feel that the taking of a genetic test may at some future stage seriously disadvantage them in some respect, then they may be reluctant to undergo genetic tests in a clinical context. There is evidence that this is already so. If this were to become widespread, then extremely important genetic screening programmes – such as those for some forms of cancer – would be adversely affected. This has implications for the health of appreciable numbers of people, and it is also relevant to public health issues.

Research

Concern that genetic analysis may adversely affect one's chance of obtaining insurance also threatens public participation in genetic research. The proposal to establish a major DNA research database in the United Kingdom, a proposal which would have far-reaching implications for progress in the treatment of disease, could be adversely affected by public reluctance to give samples for analysis. We welcome, however, the statement on genetic test results and research which was recently issued by the Association of British Insurers, the British Society of Human Genetics, and the United Kingdom Forum on Genetics and Insurance.

In view of these concerns, the HGC believes that it is vital that there should be a clear and defensible system of regulation which is capable of enjoying the confidence of the public. The setting up of such a system will involve the careful balancing of interests including those of insurers, insured persons, and the broader community. A variety of options is available, ranging from an almost complete ban on the use of genetic test results (as is found in some European systems), to a properly enforceable system in which limited use of certain results may be allowed. It seems to the HGC that at this stage the options of complete non-regulation and the option of continuing with the current system are not viable.

The task of identifying what is the best system is a major one. There is a case for this being performed by the HGC, as part of its overall enquiry into the use of personal genetic information. This would ensure consistency of approach in relation to a number of questions relating to genetic testing. The HGC has already given substantial consideration to this issue, and could continue to do so during the moratorium period with a view to making recommendations to Government. This would obviously involve further discussion with the

insurance industry, as well as continued exploration of the economic and legal issues which the HGC has already started to address.

HGC believes that the priorities for further consideration should be:

- To review the use of family history information as part of the wider review of personal genetic information following our recent public consultation;
- To identify means of ensuring access to affordable insurance for those affected by a genetic condition;
- To promote openness about underwriting decisions involving genetic factors and the information given to consumers;
- To consider wider regulatory and arbitration systems for genetic information and insurance;
- To consider the role of insurance and the use of genetic information in a reformed welfare state, and;
- To initiate a debate on the wider role of private insurance in providing access to social goods.

Human Genetics Commission
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