

Comments to inform the Government response to the House of Commons report on genetics and insurance / Human Genetics Commission.

Contributors

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Human Genetics Commission

Comments to inform the Government response to the House of Commons report on Genetics and Insurance

HGC welcomes the House of Commons Science and Technology Committee's report "Genetics and Insurance"* which has proved extremely valuable to us in our own review of the matter. Stemming from our considerations to date, HGC offers the following commentary on the wider issues covered in the House of Commons report which may help to inform the Government response.

The Commission published its advice on the use of genetic information in insurance on 1 May 2001. Our recommendations on a temporary moratorium broadly agree with the Science and Technology Committee's **recommendation 29**. Like them, we feel that this is a necessary step to restore confidence, to gather information and to look at some wider issues of the use of personal genetic information in insurance.

HGC agree with the Science and Technology Committee that legislation to deny insurers access to all genetic test results is not appropriate (**recommendation 28**). But we differ from them in concluding that legislation will be necessary to enforce the moratorium. This will need to be new legislation if existing statutory provisions (such as financial service or consumer protection legislation) are deemed to be inappropriate.

We have also noted the Association of British Insurer's (ABI) amended voluntary moratorium announced on 1 May. There are clearly some differences of emphasis and detail in the various positions, but we hope that this will not distract the Government from the underlying principle in support of a wide-ranging moratorium.

HGC has also made recommendations about what should be done during the moratorium period. We therefore strongly agree with **recommendation 11** about the need to examine the use of family history information in setting insurance premiums. HGC will be considering this further and seeking additional expert advice in preparing our final report and recommendations on the use of personal genetic information.

HGC has joined the House of Commons (**recommendations 6 and 11**) in recommending that insurers give more information about how premiums are calculated, especially where family history information is being considered. It is our impression that the main principle underpinning private insurance contracts – "utmost good faith" bears more heavily on the applicant than on the insurer. There is also an increasing presumption across society in favour of greater openness and transparency and this area should not escape this shift of emphasis.

We would also agree with the Science and Technology Committee's call for more research (**recommendation 12**). We would be interested to see whether such research needs will be considered as part of the recently announced Genetics Knowledge Parks or under the Economic and Social Research Council's programme for social research on genomics. We also believe that the insurance industry should continue to fund independent research on genetics. They should also encourage their member companies

* "Genetics and Insurance". Session 2000-01, Fifth report. HC 174. Ordered to be printed 26 March 2001.



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to consider publishing the results of their own research and analysis in peer-reviewed journals. This would add immeasurably to the knowledge of the real world insurance market and would supplement the existing mathematical modelling techniques. The Commission has also funded a small survey by the Genetics Interest Group looking at experiences of obtaining insurance and we hope to have the completed report by the end of June.

The Commission has also proposed that it will consider mechanisms to provide access to affordable insurance (**recommendation 15**). This point has been made to us repeatedly in our consultation. HGC wishes to work with experts in the insurance and actuarial profession and to consider further recommendations in this area in our final report

The Report makes a strong case for a review of the membership of the Genetics and Insurance Committee (GAIC; **recommendations 16 – 22**). HGC has previously commented on its relationship with GAIC and we would wish to be consulted on any review of GAIC as part of our remit to advise on the effectiveness of the regulatory and advisory framework. We believe that there is now an even greater need for such a committee as a means of drawing together expertise from among geneticists, patient / consumer groups and insurers. In our view, HGC has shown the benefits that can be obtained from a committee with a broad skills mix in a complex area such as this. In particular, we are convinced of the benefits of adopting a high degree of openness and transparency in order to involve and reassure the wider public.

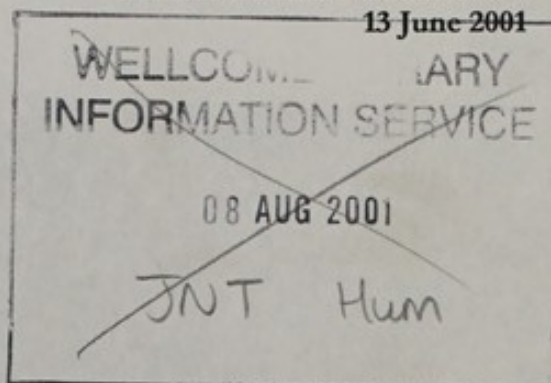
HGC shares the House of Commons' concerns about the lack of evidence on compliance with the industry Code of Practice (**recommendation 24 & 25**). We understand that compliance data will be available from the ABI in June and we may wish to comment further at that stage. There is some published evidence suggesting that those with a genetic predisposition to ill health can experience difficulties in obtaining insurance. Whilst we agree that GAIC can play a role here, we feel that the Government should also make use of new or existing statutory enforcement agencies in order to help to reassure the public that genetic test results are not being improperly used during the moratorium period.

We agree with **recommendation 31** on the need to monitor the developments in genetic testing and the wider implications. In June we will be holding a public meeting at the Sanger Centre in Cambridge to learn about technical developments in high volume genetic testing and the possible impact on a range of areas, especially insurance.

We do not know to what extent Ministers will expect HGC to conduct some of these wider reviews, and therefore precisely what additional resources we might need (**recommendation 32**). Given the complexities of the subject and the need to inform and engage the public, we can already foresee a need to fund external expert advice, surveys and modelling as well as further public consultative meetings.

Human Genetics Commission

13 June 2001



...the Committee will be able to provide a more complete picture of the situation in the field of human rights in the country. This would add significantly to the knowledge of the public and the media and would also help to bring about a more realistic assessment of the situation in the country. The Committee has also received a number of reports from the field which indicate that the situation is not as serious as it was at the time of the previous report. It is hoped that the Committee will be able to provide a more complete picture of the situation in the field of human rights in the country.

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