

SUPPLEMENTARY EVIDENCE FROM THE ASSOCIATION OF BRITISH INSURERS

The ABI is the voice of the insurance and investment industry. Its members constitute over 90 per cent of the insurance market in the UK and 20 per cent across the EU. They control assets equivalent to a quarter of the UK's capital. They are the risk managers of the UK's economy and society. Through the ABI their voice is heard in Government and in public debate on insurance, savings, and investment matters.

Introduction

Genetic science is an area of rapid growth. Our understanding of genetic information is both increasing and raising more questions. There needs to be a balance between respecting the fundamental right of individuals to privacy of their personal information, and not deterring them from making good health choices, and continuing to ensure that insurance can be provided on terms that are fair to all customers.

1. Are existing laws in the UK or in the EU, such as the Human Rights Act or the Data Protection Act, sufficient to protect individuals against genetic discrimination in employment and for insurance purposes?

The existing laws together with the regulatory framework, and the concordat and moratorium, are sufficient and provide a robust basis for the protection of insurance customers' rights. The Code of Practice, concordat and moratorium clarify and provide certainty that people will have access to substantial amounts of protection insurance and will not be required to take a genetic test for the purpose of taking out insurance.

Further, the ABI has instigated an independent arbitration service, managed through the Chartered Institute of Arbitrators and arbitrated by members of the judiciary, to ensure any customer complaints under the Code of Practice would be resolved to robust standards. This service is in addition to the FOS that in some circumstances can review insurance decisions once the contract has been signed.

2. The ABI Code of Practice for Genetic Tests applies to companies that are members of the ABI. Who is responsible for monitoring the use of genetic tests by companies who are not members of the ABI?

All companies are bound by the Access to Medical Reports Act 1998 and the Data Protection Act – controlling the access to and use of personal data, including genetic test results. The consumer must give their consent before their information can be passed to, and used by, insurers.

In addition all companies are regulated by the Financial Services Authority (FSA) and must adhere to the Dispute Resolution Complaints (DISP) process set out in the FSA handbook at: <http://fsahandbook.info/FSA/html/handbook/DISP>. Consumers are enabled to question and complain about their treatment through this regulated process. However, as confirmed by Professor David Johns, Chair of the Genetics and Insurance Committee, there are minimal complaints from consumers regarding genetic matters.

ABI members provide well over 90per cent of the protection insurance market. The market is competitive and there is ample consumer choice of insurance companies and access to protection insurance products.

3. Are there sufficient safeguards under the Moratorium and Concordat on Genetic Testing and Insurance to ensure that individuals undertaking a genetic test now protect the information for insurance purposes after 2014?

Genomic medicine is developing and the science of treatment has not yet caught up with the science of prediction. We do not know what the future of genetic medicine will hold. We want to treat customers fairly and avoid unintended consequences that would lead to inequalities in the future. Trying to future proof insurance in an environment where there is so much uncertainty is better managed through the concordat and moratorium continuing to provide certainty, clarity and flexibility on the use of genetic test results.

The agreement with government has been in place since 1999. The concordat is timeless and this confirms that insurers will not ask anyone to take a predictive genetic test to take out insurance. The moratorium agreement dates from November 2001, and is subject to regular reviews by the Department of Health and the ABI. The next review will be in 2011 and, if there is no agreement to extend it, the moratorium will end 3 years later in 2014. At both of the reviews so far, in 2005 and 2008, the moratorium has been extended. The three-year period between the review and the moratorium expiry date will allow plenty of time for people to take out insurance if that is what they want to do.

The ABI and Breakthrough Breast Cancer are working together to revise existing consumer information on the use of genetic test results and consumer groups for cancer will assess this in November 2008.

4. Huntington's disease is currently the only condition for which predictive tests are exempt from the moratorium, and this exemption is only for policies above a particular value. Are more genetic conditions under consideration for exemption? If so, which?

The ABI has no plans to submit any applications for the use of further predictive genetic tests, and will not be making any applications in 2009. The current approach works in practice because the number of policies affected by non-disclosure of predictive genetic test results is low. The proportion of life policies for cover greater than £500,000 is less than 3per cent.

There is always a risk of anti-selection where an individual has information about their health, perhaps through a genetic home testing kit, that they do need to tell, or chose not to tell the insurer. Although genomic medicine is developing there is no substantial evidence base, of the number, type, and result of genetic tests undertaken in the UK. We would support such a database of anonymous and aggregated information being developed and maintained centrally, perhaps by the Department of Health. It would be of immense value to identify trends, health outcomes and patterns of insurance buying behaviour associated with genetic test results.

5. What kind of evidence do you look at when deciding if a genetic test should be approved?

We want to protect the interests of all consumers and would look at whether there was evidence of a significant number of people of higher risk taking out a disproportionate amount of insurance to the detriment of other customers who would have to cross-subsidise them.

6. How many complaints have GAIC received from members of the public since its creation and what is the nature of those complaints?

We recognise the possibility of complaints. We expect these to be extremely rare but we have never-the-less set in place an independent arbitration service that is free to customers and managed by the Chartered Institute of Arbitrators. The Arbitrator in these cases would be selected from members of the judiciary.

7. Should individuals who are known to be at higher risk of developing early onset diseases pay more for their insurance?

The current state of genomic medicine is that there is only one predictive genetic test result that we know will develop into a disease and that is Huntington's Chorea.

The overriding principle of insurance is that everyone's premium broadly reflects the risk they present to the risk pool that they are in. However, there are questions about whether our genetic makeup should be privileged information and should therefore differ in its treatment from, say, our medical history. Accordingly, while the science is evolving quickly, the concordat and moratorium offers additional protection to consumers.

8. The Human Genetics Commission stated in their response to the Government's consultation on the Equality Bill that "there is anecdotal evidence of genetic discrimination which constitutes an adequate justification for legislation now; and that there are reasons to believe that opportunities for genetic discrimination will increase". Do you agree?

We do not agree, and we have evidence that there is no genetic discrimination in insurance. First, there is the tiny number of complaints. It is a FSA requirement that every customer is given details of how to complain before they conclude their insurance. Further, our response to Question 2 refers to consumer information regarding the complaints process, as follows: All companies are regulated by the Financial Services Authority (FSA) and must adhere to the Dispute Resolution Complaints (DISP) process set out in the FSA handbook at: <http://fsahandbook.info/FSA/html/handbook/DISP>. Consumers are enabled to question and complain about their treatment through this regulated process. However, as confirmed by Professor David Johns, Chair of the Genetics and Insurance Committee, there are minimal complaints from consumers regarding genetic matters.

Secondly, the annual genetics compliance exercise shows that firms comply with the Concordat and Moratorium. The Genetics and Insurance Committee provides comment on the compliance report and reports to Health, Treasury, and Business, Enterprise & Regulatory Reform Ministers on proposals it receives from insurance providers and the subsequent level of compliance by the industry.

However, we are not complacent and if anyone has evidence to the contrary we would be very willing to assess it and to implement solutions.

9. Is there a risk that genetic test results may be misinterpreted resulting in individuals being erroneously denied insurance or prevented from carrying out a specific job?

Insurers comply with stringent processes that ensure genetic test results are understood and applied correctly to underwriting decisions. Within insurance companies the Nominated Genetics Underwriter receives all cases involving genetic test results. Alongside the Nominated Genetics Underwriter, a medical practitioner, normally the Chief Medical Officer, receives all cases where the genetic test result will impact on the underwriting decision.

The Nominated Genetics Underwriter is a senior underwriter. Insurers pass all applications containing a genetic test result (whether predictive, diagnostic, carrier, or unknown) to the Nominated Genetics Underwriter for a decision on insurability, and to ensure the secure handling of the test result. When the Nominated Genetics Underwriter receives an application involving genetic information that could affect the underwriting decision unfavourably to the consumer, the Nominated Genetics Underwriter consults the insurance company's Chief Medical Officer (CMO), before reaching a decision. The Chief Medical Officer provides expert advice and where necessary consults a genetics specialist. Whether the medical adviser is a Consultant Physician or a GP, he or she is accountable to the General Medical Council for his or her professional conduct.

10. In the US the Genetic Information Non-discrimination Act (GINA) came into force recently. Is there a need for a similar law in the UK?

We should be clear that in the US GINA only applies to their version of private medical insurance. This should be set in the context that there is no equivalent of the NHS. For these reasons it is not comparable with the UK health and insurance systems.

The UK offers universal entitlement to State benefits and healthcare. Taking out private insurance, such as, Income Protection insurance, is a consumer choice for people who feel they need additional protection to that afforded by health and unemployment benefits provided by the State.

When considering the various legislative and other means of regulating the use of genetic information that are used around the world, one needs to set the individual solutions in the context of the underlying State support and insurance markets that operate in those countries.

It is worth noting that a complete ban on insurers using any predictive genetic test result would mean that people with favourable results could not use this to offset other adverse health conditions.

**Association of British Insurers
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