

# GENETIC TESTING IN INSURANCE AND EMPLOYMENT: A New Form of Discrimination



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Developments in genetics mean that there will be increasing numbers of tests to detect genes associated with disease. How this information is used will be crucial to determining the effect which genetic science will have on society. Although a genetic test may result in the patient receiving an effective treatment, the identification of an untreatable disease could be psychologically damaging for the individual and their family. Genetic test information could also be used to discriminate against a person as grounds for refusing insurance cover or employment. In such cases, people could be required to have genetic tests or to disclose the results of tests already taken. This briefing considers genetic tests, their potential abuse and the safeguards which are necessary to prevent them being used for discriminatory purposes.

## GENETIC TESTS

By comparing the genes of people affected by a particular disease with genes from those who are unaffected, scientists can identify genes which are different in the two groups and therefore the gene (or genes) which may be associated with the disease. The actual differences between a faulty gene and a normal gene can be very small – only one or two of the chemical bases making up the gene may be altered – or very large - with whole sections of the gene deleted or containing repeated sections. The theory is that affected genes do not work properly and this results in the illness, although this relationship is far from simple and is influenced by many environmental factors.

Genetic tests are conducted on a sample of a person's DNA (which makes up the genes) that has been isolated from blood or tissue to identify whether a gene is faulty. The information can then be used:

- to confirm a diagnosis (that a person has haemophilia, cystic fibrosis or another

genetic disease);

- predictively to try to determine whether they may develop a disease in later life (such as some forms of breast cancer);
- to test whether a person carries a faulty gene which could be passed on to their children (e.g. cystic fibrosis) although they have a normal copy as well which prevents them developing the disease themselves.

However, although scientists can identify differences between genes, it is much more difficult to determine their exact role in a disease or to predict the course of the disease in a person who has a faulty gene<sup>1,2</sup>. Even with diseases which are thought to be caused by a fault in a single gene (known as monogenic disorders) there can be considerable variation in the severity and time of onset of the illness. One of the best researched single-gene disorders is  $\beta$ -thalassaemia, where red blood cell production is impaired and patients are anaemic. However, people carrying the  $\beta$ -thalassaemia gene may be completely healthy, mildly affected or severely anaemic and over 180 different abnormalities in the gene have been identified, illustrating how complex even apparently simple genetic disorders can be<sup>2</sup>.

With breast and ovarian cancer, 5-10% of cases are associated with defects in the BRCA1 and BRCA2 genes but this does not mean the cancer will develop (estimates range from 36-85% for breast cancer and 10-44% for ovarian cancer for women carrying the gene) and the age of onset varies widely. These variations are associated with many other factors including environment, other genetic effects and random processes which are not understood<sup>1</sup>. Other genetic disorders are equally unpredictable and even with Huntington's Disease, where the disease is considered almost inevitable if a person carries the gene, the age of onset may vary over several decades.

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Professor Bobrow, Head of Medical Genetics at Addenbrooke's NHS Trust told the House of Commons Select Committee: "*Genetic tests are very good at distinguishing those who carry a particular gene from those who do not. They are somewhat less accurate at identifying those who will and will not eventually get the disease.*"<sup>3</sup>

For an individual patient, as well as the uncertainty inherent in the predictability of a test, its usefulness will depend on a whole host of factors, particularly whether the disease is treatable. For certain genetic diseases such as multiple endocrine neoplasia type 2 and haemochromatosis, effective prophylactic treatments are available so testing has a clear benefit. However, the potential for insurers and employers to discriminate on the basis of genetic test data could be a powerful deterrent to taking the test in the first place.

Where there are no treatments, requiring someone to take a genetic test could be almost as harmful as the genetic fault itself. For conditions such as Alzheimer's Disease, for instance, where certain genetic faults indicate an increased risk but there is no treatment, anxiety and stigmatisation are the most likely outcome for those with positive tests. Furthermore, the intense complexity and poor predictive power of genetic testing means that using the data as grounds for discrimination could be entirely misguided.

## **INSURANCE AND GENETIC TESTING**

There are four main areas of insurance where genetic test data is relevant:

- life insurance (life insurance as part of a mortgage makes up around half of all life policies);
- disability income insurance (monthly benefit in the case of long term illness or disability);
- long-term healthcare insurance;
- critical illness insurance (a lump sum paid upon the diagnosis of a serious illness).

Such commercial insurance schemes are based on 'mutuality', where purchase is optional and a request for insurance can be refused or premiums adjusted up or down according to what the risk is calculated to be. The insurance industry argues that it would be unfair to prohibit access to accurate information about an individual's health as this is essential to calculating risk.

In contrast, the UK's National Health Service and Social Security systems are forms of 'solidarity' based insurance. Contributions are compulsory (based on ability to pay) and benefits are shared according to need with no relationship between the two. Genetic testing is therefore not relevant in the same way. However, the Government's commitment to increasing private long-term social and health care means this may change.

The insurance industry has been keen to have access to genetic test data because it believes that<sup>4</sup>:

1. If people have genetic tests which reveal a problem and they do not disclose the result, they may try to obtain extra insurance so that they (or their beneficiaries) can claim on the policy. This is known as 'adverse selection' and the industry believes it could lead to considerable financial losses for insurers.
2. Genetic test information will provide reliable data for estimating risk and a fair basis upon which to discriminate in the UK as private insurance is more of a luxury than a necessity or a public service.

3. Family histories which provide information on hereditary diseases are already used to assess risks so more accurate genetic tests should also be allowable.
4. People who do not have abnormal genetic test results will have to subsidise those that do if these are not disclosed.

Given the sensitive nature of genetic information, these claims need to be critically evaluated to assess their validity.

**Adverse selection?** The insurance industry argues strongly that it will be economically disadvantaged if customers have access to health information which they do not disclose and that people who know they have genetic defects will take out insurance and exploit the system. This 'adverse selection' is the main pillar of their argument to gain access to genetic information. Much of the evidence which has been presented on this subject is theoretical and conjectural rather than being based on actual behaviour<sup>5</sup>, although experiences with HIV/AIDS have made insurers wary. However, a recent study of women in the USA with the breast/ovarian cancer susceptibility genes, BRCA 1 and 2, has shown that they did not seek out life insurance and their behaviour in relation to insurance was determined not by their genetic test results but by the normal drivers of insurance such as household income, age, marital and employment status<sup>6</sup>.

Potential financial losses would be further restricted since the actual numbers who could be involved in adverse selection are extremely limited. Only about 3% of all cases of illness can be directly associated with single gene disorders and, of these, it is only a very few late onset genetic disorders - rather than those affecting children - which are likely to have any impact<sup>7</sup>.

**Reliable testing for a luxury product?** In a country which has universal healthcare and a social security system, it is tempting to argue that private life and health insurance are not essential and should be a preserve of the market place. However, such an assumption is less convincing when viewed in the broader social context of a housing system based on home ownership and the allied demand for life insurance cover and the increasing pressure on individuals to make provision for themselves and their families in later life.

If private insurance is, in reality, a necessity for a reasonable standard of living and there are social expectations to participate, the use of genetic testing becomes a form of discrimination rather than fair practice. The potential to create a genetic underclass which is uninsurable and socially excluded as a result becomes very real. This is particularly disturbing as insurers are unlikely to be able to evaluate accurately even relatively straightforward single gene disorders given the variability in disease severity and age of onset. A lack of accuracy and false assumptions about risk would put those affected at a serious disadvantage. In a survey of people affected by certain genetic diseases in the UK, 33% had experienced difficulty obtaining life insurance, including some of those who carried a gene defect but would not develop the disease<sup>8</sup>. A survey of US medical directors of life insurance companies showed that although they were interested in using genetic test information, their interpretation was subjective and some did not understand basic principles of medical genetics<sup>9</sup>.

If the insurance industry believes that it will be able to use genetic tests to predict complex disorders such as asthma and heart disease - where environment and lifestyle are more important - not only will the assessment task be enormous but it is likely to be inaccurate.

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**Family histories so why not genetic information?** When applying for insurance, people are asked to give information not only about their own health but also their relations' health. This is intended to help the insurer identify any possible hereditary diseases which may affect the risk. The insurance industry argues that if this information is allowable, why not genetic test data? The important question here is whether family history data is reliable and used properly by insurers. Much evidence suggests that people may be very uncertain about illness and causes of death in their relations. Other evidence suggests that insurers misinterpret family history data and its ability to predict disease in an individual<sup>10</sup>. This means that rather than legitimising the use of genetic information, the use of family history data itself should be questioned. This has been recognised elsewhere and in the Netherlands any information about hereditary diseases cannot be used by insurers except for very high value policies (see Table 1).

**Healthy people will have to pay more?** It is also argued that people who do not have any genetic defects will be penalised by having to pay higher premiums if genetic test data is not disclosed. This presumes that people would rather leave those with genetic defects to suffer than share the risks more equitably. However, a recent survey of public attitudes by the Human Genetics Commission has shown that four out of five people believe that genetic information should not be used in setting insurance premiums<sup>11</sup>.

### **The Legal Situation in Britain**

It is widely agreed both in Britain and elsewhere that people should not be required to undertake genetic tests for insurance purposes. The debate centres on whether any existing genetic test data should be disclosed. However, there are no laws in Britain which control the use of genetic information by insurers. The situation has been left to evolve through self-regulation by the industry via a code of practice established by the Association of British Insurers (ABI). However, a damning report by the House of Commons Select Committee on Science and Technology revealed that companies were not observing their own guidelines and were confused about their meaning<sup>3</sup>. Because there was no clear justification for the 10 genetic tests for 7 conditions the ABI wished to use (from the many thousands of rare genetic disorders) and the Royal Society evidence suggested that their choice was 'arbitrary', the Select Committee concluded that: "*Insurers appear to have been far more interested in establishing their future right to use genetic test results in assessing premiums, than in whether or not they are reliable or relevant*". The inclusion of insurance industry representatives and advisors on the Government's advisory committee, the Genetics and Insurance Committee (GAIC), was also criticised.

In response to the Select Committee Report and a similarly critical report from the Human Genetics Commission (HGC)<sup>10</sup> on 1st May 2001, the ABI announced that it was to extend its partial voluntary moratorium on the use of genetic test results to all policies up to £300,000 - some £200,000 less than the HGC proposed<sup>12</sup>. Above that level, only tests approved by GAIC would be required to be disclosed.

Currently, GAIC has approved two genetic tests for Huntington's Disease for use in life insurance, giving Britain the unenviable reputation of becoming the first country to officially sanction genetic testing for insurance purposes<sup>13</sup>. Approval is also being sought for the use of genetic tests to detect familial, early onset (hereditary) Alzheimer's Disease and hereditary breast and ovarian cancer (BRCA 1 & 2). Whether these will be approved is uncertain until after

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the Government has responded to the HGC's report.

## The Legal Situation in Other Countries

In contrast to the UK, many other countries have already introduced legislation to restrict or prohibit the use of genetic test information by insurers and this is summarised in Table 1. In part, differences in legislation have arisen depending on whether there is some form of universal healthcare like the NHS. For example, in the USA, where people depend on private healthcare insurance, the pressure not to use genetic test data has been greater.

**Table 1: Legislation in other countries regulating the use of genetic information by insurers** <sup>14,15</sup>

Country	Regulation	Effect on Insurers
Austria	1994 Gene Technology Act	Use of genetic test information by insurers prohibited
Australia	Voluntary agreement	Insurers will not request genetic information
Denmark	1997 Act 413 on Insurance Agreements and Pension Funds	Prohibits insurers requiring, obtaining or receiving genetic information
Netherlands	1998 Medical Examinations Act	Insurers not allowed to enquire about genetic tests or hereditary disease. Exemption for high coverage
Norway	1994 Act Relating to the Application of Biotechnology in Medicine	Illegal to request, receive, retain or make use of genetic test information
Sweden	1999 agreement between Swedish Government and Association of Insurance Companies	Prohibits use of genetic information
USA	1996 Health Insurance Portability and Accountability Act	Prohibits insurance exclusions on the basis of genetic test results
	State regulations	Varying state laws according to type of insurance and information

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## EMPLOYMENT AND GENETIC TESTING

The use of genetic test information by employers has received much less attention than its use by insurers. In the area of employment, requiring people to take genetic tests as well as disclose existing test information is being considered. Employers might want to use genetic test data to identify and avoid employing a person who may:

1. have prolonged periods off work due to ill health;
2. be more at risk of an occupational illness;
3. put others at risk through a sudden attack of an illness (such as an airline pilot).

These justifications for requiring test data have little scientific basis and could not only result in unfair discrimination but also lead to deteriorating standards in the workplace. As described earlier, the predictive ability of genetic tests is extremely poor and employers are unlikely to be able to deal with such complex information. The likelihood, therefore, is that they would fall back on prejudice to

***The use of genetic test data for employment purposes could result in unfair discrimination and deteriorating standards in the workplace***

make choices. Complex disorders - including occupational diseases - where there is a combination of environmental and genetic influences, could lead to an inclination to search for the 'right' employee genetically rather than improving workplace conditions. Whilst the use of test information to protect others sounds sensible, there are currently no examples of how genetic testing would help. Single-gene disorders are unlikely to be sudden in onset and thus lead to an aircraft accident for example, and the multi-factorial nature of sudden onset illness such as heart disease means it will be impossible to use genetic tests to predict with any accuracy whether or when a heart attack may occur. Again, it is more likely that ignorance and prejudice would take precedence in decisions about employment.

Experiences in the USA in particular suggest that genetic information could be used to discriminate against people. For example, a recent American survey<sup>16</sup> revealed 582 cases of people who were refused jobs or health insurance because of 'flaws' discovered in their genes. Disturbingly, the US Department of Labour has also found that: "*many women are avoiding breast cancer screening because they believe a positive finding would go on their medical records and become available to employers or insurers*"<sup>16</sup>. Very recently, a US rail company has been taken to court for demanding a genetic test for carpal tunnel syndrome when employees make a claim for work-related injuries related to the condition<sup>17</sup>.

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Problems in the US may reflect the different healthcare situation as most employers provide healthcare insurance as part of the employment package. However, they also highlight the potential for discrimination which may increase in the UK with the Government's policy of increasing private provision of long-term healthcare. Only one UK employer, the Ministry of Defence, screens employees (air crews) for a genetic disorder, sickle cell disease, which may cause problems for non-symptomatic carriers when exposed to high altitude. However, a study by the Health and Safety Executive showed that around one third of employers in Britain carry out health based pre-employment assessments<sup>18</sup> so the potential for the use of genetic test information is real.

### **The Legal Situation in Britain**

In the UK, there are no regulations specifically dealing with the issue of genetic information and employment. The Disability Discrimination Act 1995 provides some protection against discrimination for existing disabilities but not those which are not yet symptomatic. As the Human Genetics Advisory Committee (HGAC, the forerunner of the Human Genetics Commission) observed in 1999:

*"An employer may lawfully require a prospective employee to undergo genetic testing as a condition of obtaining appointment and may request an employee to submit to such a test. It is not unlawful to discriminate on the basis of the result of such tests".<sup>19</sup>*

In response to this situation, the HGAC produced a set of non legally binding policy guidelines which state that:

- 1) *An individual should not be required to take a genetic test for employment purposes – an individual's 'right not to know' their genetic constitution should be upheld.*
- 2) *An individual should not be required to disclose the results of a previous genetic test unless there is clear evidence that the information it provides is needed to assess either current ability to perform a job safely or susceptibility to harm from doing a certain job;*
- 3) *Employers should offer a genetic test (where available) if it is known that*

*a specific working environment or practice, while meeting health and safety requirements, might pose specific risks to individuals with particular genetic variations. For certain jobs where issues of public safety arise, an employer should be able to refuse to employ a person who refuses to take a relevant genetic test;*

*4) Any genetic test used for employment purposes must be subject to assured levels of accuracy and reliability; and*

*5) If multiple genetic tests were to be performed simultaneously, then each test should meet the standards set out in (2), (3) and (4).*

The proposed code of conduct under the Data Protection Act, which could apply to personal genetic data, also relies on these guidelines.

However, there are no genetic tests currently available - or likely to be in the foreseeable future - which would give reliable information on ability to do a job or whether an employee would place others at risk or be at risk themselves. As with genetic testing and insurance, the desire to keep the door open to the use of genetic tests has dominated the UK Government's attitude<sup>20</sup> despite the greater opportunity for abuse than benefit to workers.

## **The Legal Situation in Other Countries**

Some countries have enacted specific regulations to protect workers. In Austria, employers are prohibited from requesting or collecting genetic information in employment and in Norway and France, genetic testing for employment is illegal<sup>21</sup>. In the USA, 23 states have laws regulating the use of genetic information in employment practices. In several of these states, it is specifically illegal to use tests for genetic diseases which are associated with particular racial groups such as sickle cell trait and Tay-Sacs disease. In 2000, President Clinton also made an order prohibiting public departments and agencies from using genetic information in employment including family history information<sup>15</sup>.

## **CONCLUSIONS**

There appears to be a conviction in the UK that genetic testing will eventually be sufficiently accurate to justify its use in predicting risk of illness and death and assessing employability. This underpins policy commitments which seek to maintain the possibility of using genetic testing in insurance and employment.

However, there is a Council of Europe 'Convention on Human Rights and Biomedicine' which prohibits "any form of discrimination against a person on grounds of his or her genetic heritage". Since employment and insurance - even health insurance - are not luxuries in the UK, allowing genetic testing to be used constitutes a form of discrimination. The poor predictive capacity and arbitrary nature of test selection reinforces the unfairness of using genetic constitution as a basis for discrimination. Prejudice has had a long history of looking for physical signs - skin colour, sex or disability - as a means by which to discriminate. Gene testing is a physical measurement on a finer scale which has no better basis upon which to make accurate judgements about a person's future health or ability to undertake a job.

Furthermore, whilst there are no laws to ban the use of genetic test data by insurers and employers, the fear of discrimination may deter people from participating in research to discover new treatments or from taking tests which could lead to treatments for their own condition. To benefit from the new genetics, one vital safeguard must be that genetic data cannot be used to

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***The poor predictive capacity and arbitrary nature of test selection reinforces the unfairness of using genetic constitution as a basis for discrimination***

discriminate against a person in insurance or employment and legislation is urgently needed to enforce this. Increasingly, the UK lags behind the rest of the world. President Bush, for instance, recently announced that he will support legislation against genetic discrimination because it is: *"unfair to workers and their families. It is unjustified.... because it involves little more than medical speculation"*<sup>22</sup>.

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