



Genetic discrimination by insurers and employers: still looming on the horizon

An update on the use of genetic test results by employers and insurers

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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. A genetic test may result in the patient receiving an effective treatment. However, because of the complex interactions between a person's genes and the environment involved in most common conditions, simply knowing that someone has a particular gene often provides very limited information about their current or future health. However, 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 (for example, as part of a pre-employment medical check) or to disclose the results of tests already taken (as part of applying for an insurance policy).

GeneWatch UK believes that legislation is needed to prevent insurers and employers from using predictive genetic test results to decide who gets insurance or a job. This briefing updates our previous reports and briefings by providing:

1. A guide to the types of tests that are available and evidence that employers and insurers are interested in using them;
2. Recent cases of genetic discrimination and evidence that the prospects of discrimination may deter people from taking genetic tests;
3. A summary of laws around the world to prevent genetic discrimination.

Types of genetic tests

The two main types of genetic tests are of:

- the genetic make-up or genotype that a person is born with;
- genetic damage that occurs during a person's lifetime.

Tests of genetic damage can legitimately be used in the workplace as part of monitoring the damaging effects of hazardous chemicals and radiation on a person's DNA. Concerns about genetic discrimination focus not on monitoring genetic damage, but on tests of the genetic make-up that people are born with. These tests can reveal whether a person:

(i) has a *genetic disorder*, including a few rare conditions such as Huntington's Disease, where a person may not develop any symptoms until later in life. The severity of symptoms, and when or whether they will affect a person's ability to do their job, is not predictable.

(ii) is at *increased risk of developing a common disorder* such as cancer or heart disease. Currently these type of tests are available only for relatively rare 'familial' (largely inherited) forms of these common disorders (for example, mutations in the BRCA1 and BRCA2 genes account for about

5% of cases of breast cancer). A person with one of these genes will be at increased risk but will not necessarily develop the condition. Researchers disagree about whether this type of test is likely to prove useful in predicting the risk of common diseases in a much larger number of people in the future.

(iii) is at increased risk of developing a condition such as asthma or cancer *when they are exposed to hazardous chemicals or radiation in the workplace*. Much research effort has focused on this type of genetic test, but none has been firmly established as good at predicting which workers will get ill. Although in theory these tests could be used to protect the health of vulnerable workers, many geneticists and trade unions argue that using them could do more harm than good. Concerns include the low predictive value of genetic tests; that screening and excluding some workers could undermine efforts to reduce exposures and make the workplace safe for all; and the harmful impacts on excluded workers (such as unemployment). These concerns have been raised widely including by academics in Belgium¹ and the USA;² the National Work Rights Institute in the USA;³ and the Center for Human Genetics in Belgium.⁴

An example of a test for genetic susceptibility to pesticide exposure is given in Box 1.

Box1. Case study: the PON1 gene and susceptibility to pesticides

Research on genetic susceptibility to organophosphate (OP) pesticides (such as sheep dip) has suggested that a number of genes may play a role, particularly a gene called PON1. Some recent research on PON1 and sheep dip has been funded by the UK Health and Safety Executive (HSE) at the University of Manchester:⁵

This type of research can help improve worker safety by improving understanding of how sensitivity to pesticides develops. But it could also be used to argue for the exclusion of “genetically susceptible” workers. However, a detailed study has concluded that the health benefit of genetically screening pesticide workers would be limited and could be harmful and unethical. This is because:⁶

- the predictive value of the test is limited;
- many other factors are likely to influence whether a pesticide worker becomes ill;
- alternative approaches (such as reducing exposures or monitoring health) may be better for health.

Tests for many genetic disorders and for the familial forms of common disorders are available in the National Health Service. Tests for ‘genetic susceptibility’ to conditions such as heart disease, or to exposure to some chemicals, are already commercially available on the internet and in some shops in the US. For example, many genetic tests linked with dietary advice include genes thought to be connected with the processes involved in breaking down hazardous chemicals.⁷ These tests have been widely criticised by geneticists as potentially misleading.⁸ This is because:

- (i) most statistical studies linking genes to common diseases later turn out to be wrong;
- (ii) even if a gene does play a role in susceptibility it usually is only one of many complex factors and has only a small effect. The marketing of these tests is likely to increase in future.

¹ <http://www.genetic-testing-and-work.be>

² <http://ehp.niehs.nih.gov/members/1996/Suppl-5/holtzman.html>

³ http://www.workrights.org/issue_genetic/gd_fact_sheet.html

⁴ http://www.iph.fgov.be/aph/pdf/aphfull62_15_22.pdf

⁵ <http://www.hse.gov.uk/research/rrpdf/rr408.pdf>

⁶ <http://depts.washington.edu/ceeh/issues/PON.pdf>

⁷ <http://www.guardian.co.uk/genes/article/0,2763,665829,00.html>

⁸ <http://education.guardian.co.uk/higher/news/story/0,,1697963,00.html>

Current law does not protect people from being discriminated against on the grounds of a supposed 'genetic susceptibility'. People who have the *symptoms* of a genetic disorder (i.e. who meet the definition of 'disabled') are covered by the Disability Discrimination Act (DDA). This means that employers are legally obliged to make reasonable adjustments to the workplace, and are not supposed to discriminate against them by refusing them work. But people who have *predictive* genetic tests – whether they predict the later onset of a genetic disorder, or susceptibility to a common condition such as cancer – are not protected from discrimination by the DDA.

Evidence that employers and insurers are interested in using genetic test results

The availability of genetic tests and their potential for leading to discrimination would not be so great if employers and insurers were not interested in the information they provide. However, the evidence below demonstrates that both insurers and employers would like to use predictive genetic test results in decisions about employment and insurance.

The Institute of Directors' survey (UK, 2000)

In 2000, the Institute of Directors conducted a survey of employers' views on health testing at work in the UK.⁹ The 353 responses on genetic testing are shown in the table below. There was particular interest in testing for 'genetic susceptibility' to workplace-related disease. Many employers were also interested in genetic testing for susceptibility to conditions such as heart disease, which might affect early retirement. It seems likely that these employers were interested in trying to cut the costs of occupational insurance schemes, compensation payouts, and pensions.

Question: "Would it be appropriate for employers to conduct genetic testing of employees?"

REASON	YES, IF EMPLOYEE CONSENTS	YES, COMPULSORILY IF IN EMPLOYEE'S BEST INTERESTS	NO	NO REPLY
To see if they will develop heart disease which might affect sickness or early retirement	34%	8%	56%	2%
To see if they are at risk of developing an occupation related disease due to exposure in the workplace	50%	16%	30%	3%

353 questionnaires received. Total may not be 100% because of rounding.

The UK insurance industry

Most (but not all) insurance companies in the UK are members of the Association of British Insurers (ABI). Following much controversy about the use of genetic tests to set premiums or refuse cover, the ABI has agreed a voluntary moratorium on the use of most predictive genetic test results until November 2011. However, this agreement is partial, temporary and not legally binding. As part of the ABI's agreement with the Government, insurers have been given the right to use genetic tests in underwriting decisions in the future, provided the use is 'transparent, fair and subject to independent oversight'.¹⁰

⁹ Day G (2000) Testing Times: Directors' Views on Health Testing at Work. *Institute of Directors Research Paper*.

http://www.iod.com/intershoproot/eCS/Store/en/pdfs/regulation_publications_policypapers_healthwork.pdf

¹⁰ <http://www.dh.gov.uk/assetRoot/04/10/60/50/04106050.pdf>

The Confederation of British Industry (CBI)

In 2004, the CBI opposed inclusion of legislation against genetic discrimination in a proposed 'Single Equality Bill for Northern Ireland' on the grounds that genetic predisposition was 'self-evidently unsuitable' as a basis for workable equality legislation.¹¹ In taking this position, it seems the CBI sees an interest in maintaining the ability to discriminate on the basis of genetic test results.

Genetic testing by US companies

Decisions made by US companies – either to use or not to use genetic tests – could have a major impact on policies world-wide. Therefore, what is happening in the US is relevant to the debate in the UK and rest of Europe. In 2001, the American Management Association (AMA) conducted a survey of its members about workplace medical testing and received useable replies from 1627 companies.¹² Two firms said they used genetic tests to detect heritable disease (the definition included predicting risk of disease and identifying carriers). However, a much larger percentage (14.3%) – some 230 firms - reported testing for 'susceptibility to workplace hazards'. Not all 'susceptibility' testing is necessarily genetic testing, however it is likely that at least some of these tests were genetic.

The AMA repeated the survey in 2004, when it received useable responses from only 503 firms.¹³ The 2004 survey did not include the category of genetic testing, but 3% of firms responding tested employees and/or job applicants for breast or colon cancer (this may include some genetic tests, as they are available to test for susceptibility to familial forms of these conditions); 2% for sickle cell anaemia (a genetic disorder); 0.8% for Huntington's Disease (a late-onset genetic disorder); 14.7% for family medical history; and 15.1% for 'susceptibility to workplace hazards' (a category likely to include some genetic testing). Some of these tests were used in decisions about who to hire and who to dismiss.

In October 2005, IBM became the first major company to pledge *not* to use genetic screening in the workplace.¹⁴

Cases of genetic discrimination

Genetic discrimination is most prevalent in the USA, because employers usually pay for their employees' health insurance. Because there is no effective safety net for people denied health insurance, the issue has also been particularly controversial there. Many States have banned genetic discrimination and there is currently a major campaign to pass a national law.¹⁵

There have also been examples of genetic discrimination in Europe and Australia. Even where genetic discrimination is not yet widespread, there may be considerable uncertainty about whether a genetic test will be used to exclude someone from insurance or employment in the future. This uncertainty may affect people's decisions whether or not to take a genetic test, rather than allowing them to make the decision on medical grounds alone. There is evidence that some people may not take genetic tests because of fears about discrimination, or they may refuse to take part in research.

Genetic discrimination in the USA:

In October 2004, seven people gave evidence about genetic discrimination or fear of discrimination to the US Secretary's Advisory Committee on Genetics, Health, and Society. They described how tests for the genetic disorders alpha-1 antitrypsin (AAT), Huntington's Disease and haemophilia, and

¹¹ [http://www.cbi.org.uk/ndbs/positiondoc.nsf/0/b04f5597e428b01980256f5c003e7663/\\$FILE/ni1704singleequality.pdf](http://www.cbi.org.uk/ndbs/positiondoc.nsf/0/b04f5597e428b01980256f5c003e7663/$FILE/ni1704singleequality.pdf)

¹² http://www.amanet.org/research/pdfs/mt_2001.pdf

¹³ http://www.amanet.org/research/pdfs/Medical_testing_04.pdf

¹⁴ http://www.businessweek.com/technology/content/oct2005/tc20051011_9733_tc024.htm

¹⁵ <http://geneticfairness.org/index.html>

for genetic susceptibility to familial breast and ovarian cancer, had affected access to insurance and employment for them or their families, or affected their decisions whether or not to have a genetic test (see boxes below).

Box 2. Healthy children denied health insurance

Heidi William's two children were twice denied health insurance by the company, Humana, because they were carriers of the genetic disorder, alpha-1 antitrypsin deficiency, or AAT. Because the children had one normal and one abnormal copy of the gene, they would not have had any symptoms of the liver or lung disease that AAT causes. It was only when the media became involved in the issue that Humana reversed its decision. "Humana, Inc. made me feel guilty and ashamed for needing to know my children's genetic status," Mrs Williams told the hearing.¹⁶

Box 3. Fear of genetic discrimination prevents genetic testing on medical grounds

Phaedra Malatek of Aurora, Illinois comes from a family with members who suffer from the genetic disorder, hemochromatosis. She told the hearing that she had not tested her children to see if they carried the gene for the condition because she was afraid they would not be able to get health insurance - even though being tested for the condition might improve the opportunities for appropriate treatment when needed.

"As it stands right now, if my children undergo genetic testing for hemochromatosis, they risk not being able to obtain health insurance when they're no longer covered under my husband's policy and possible discrimination when they seek employment," Mrs Malatek said.¹⁷

Box 4. Fear forcing people to hide genetic knowledge

Mrs Rebecca Fisher, whose mother and grandmother had both had breast cancer, told the hearing that she and her 21year old daughter would be forced to hide the fact that they carried the BRCA1 gene, which increases their risk of developing breast cancer. She feared that her daughter would not be able to get health insurance.

"I fear for my children, especially for my daughter, who must live not only with an exponentially higher risk of developing a terminal disease but also with the burden of never knowing whether or when she will legally be asked to take a genetic test as a condition of employment, be lawfully fired from a job because she's very likely to get breast cancer, or be legitimately denied health insurance or life insurance on the basis of her genetic predisposition to disease" she told the inquiry.¹⁸

Box 5: Extra health insurance costs

Tonia Phillips had a hysterectomy and prophylactic mastectomy when she learnt that she was carrying the BRCA1, breast cancer susceptibility gene. As a result, the health care premiums for the small company she worked for were increased and she was asked to change insurance companies. She did not want to do this and eventually all employees had to pay half of their insurance premiums. "It seems unfair to me that I am taking steps to keep myself healthy and to prevent cancer in the future, and I am being singled out and made to feel I am a liability," she said.¹⁹

¹⁶ http://www4.od.nih.gov/oba/SACGHS/meetings/October2004/transcript/Williams_trans.pdf

¹⁷ http://www4.od.nih.gov/oba/SACGHS/meetings/October2004/transcript/Malatek_trans.pdf

¹⁸ http://www4.od.nih.gov/oba/SACGHS/meetings/October2004/transcript/Fisher_trans.pdf

¹⁹ http://www4.od.nih.gov/oba/SACGHS/meetings/October2004/transcript/Phillips_trans.pdf

Box 6. Putting off genetic testing

Paula Funk comes from a family where breast and ovarian cancer is common. Many women in the family had not taken the test to see whether they had a breast cancer susceptibility gene because of fears that they would not be able to obtain insurance cover. Paula eventually had a genetic test because she wanted to be able to consider having preventive treatment. She has the BRCA1 gene and now fears for her twin daughters and how discrimination may influence their decisions about their health care. "There was a point where the fear of death just outweighed my fear of discrimination. That's why I pushed through with being genetically tested in spite of my fears," Paula Funk told the committee.²⁰

Box 7. Fears for their children

Maria Carolina Hiestrosa is the vice-president of the National Breast Cancer Coalition. She also comes from a family with a strong history of breast cancer. She told how many women did not volunteer to take part in genetic research, possibly delaying the development of treatments, because of fears of discrimination. She explained her own reasons for not taking a genetic test: "I sought genetic counseling as part of a study. After carefully weighing the potential benefits and harms of genetic testing, I decided not to undergo testing for fear of potential consequences to my daughter. My fears are two-fold, first that the information may not be protected and might even be misused. I also worry that if I test positive, my daughter might be obligated to disclose the presence of a genetic mutation and that she might suffer future discrimination in health insurance and employment as a consequence".²¹

Box 8. Discrimination extends to grandchildren

Phil Hardt has two genetic disorders, haemophilia and Huntington's Disease. He has had to hide his condition from employers because of fear of discrimination. His children and grandchildren are being denied insurance without genetic testing for Huntington's Disease, "Open communication is almost nonexistent between parents and their at-risk children regarding how they can better prepare to minimize the destruction of HD if they do have it," Mr Hardt told the inquiry.²²

Many other cases of genetic discrimination have been reported in the USA. One important case was settled out of court in 2001, leaving the law untested. Burlington Northern Santa Fe Corporation (a railway maintenance company) had been charged with illegally testing workers for genetic susceptibility to carpal tunnel syndrome (repetitive strain injury), when they filed claims for compensation. The company paid \$2.2 million to settle the charges.²³

According to a 2002 survey, most Americans (85%) do not believe that employers have the right to know the results of a genetic test that indicates increased risk of disease.²⁴

Genetic discrimination in the UK?

As far as GeneWatch knows, genetic tests are not yet being used by employers in the UK. However, there is no legislation to prevent employers from using genetic tests to decide who should get a job.²⁵

²⁰ http://www4.od.nih.gov/oba/SACGHS/meetings/October2004/transcript/Funk_trans.pdf

²¹ http://www4.od.nih.gov/oba/SACGHS/meetings/October2004/transcript/Hiestrosa_trans.pdf

²² http://www4.od.nih.gov/oba/SACGHS/meetings/October2004/transcript/Hardt_trans.pdf

²³ <http://www.washingtonpost.com/ac2/wp-dyn/A34877-2001Apr18?language=printer>

²⁴ <http://www.dnapolicy.org/content/pdfs/5/27375.pdf>

²⁵ <http://www.genewatch.org/HumanGen/Publications/Reports/GeneticTesting.pdf>

Although insurers cannot currently use most genetic test results, there is no guarantee that a genetic test taken today will not be used against a person in the future. Research by the charity, Breakthrough Breast Cancer, has shown that insurance industry use of genetic tests would be likely to affect whether or not some women take a genetic test. Twenty eight per cent of a group of women with a family history of breast cancer said that they would be deterred from taking a test if insurers could use the result to set premiums or refuse insurance.²⁶ The Genetics and Insurance Committee (GAIC) assesses applications by the insurance industry to use genetic tests. An application to use the results of the BRCA1 and BRCA2 genetic tests to predict risk of familial breast and ovarian cancer is expected later in 2006. If approved, test results would initially only be used for high value insurance policies, but this could change once the current voluntary agreement between the industry and the Government runs out in 2011.²⁷

The Information Commissioner has advised employers only to seek information through genetic testing as “a last resort”, and to inform the Human Genetics Commission of any proposals to use genetic testing for employment purposes.²⁸

Genetic discrimination in the European Union

Many European countries have laws against genetic discrimination, however they vary greatly, so there is no consistent level of protection at the EU level.²⁹ The first cases of genetic discrimination are emerging. In Germany in 2004, a teacher was refused a job on the grounds that members of her family have Huntington’s Disease and that she is therefore at risk of developing the disease herself. The assessment also considered she was at higher risk of absenteeism because of the prevalence of the condition in her family.³⁰

Although protection should be afforded through the European Convention on Human Rights and Biomedicine which prohibits genetic discrimination, several countries including Germany, Ireland and the United Kingdom have not signed or ratified it.³¹

The European Group on Ethics has advised that genetic testing should not be used in the workplace except in “exceptional circumstances”.³²

Genetic discrimination in Australia

The Genetic Discrimination Project in Australia analysed questionnaires completed by more than 1,000 people who had taken predictive genetic tests for susceptibility to serious diseases, such as neurodegenerative disorders and cancer. In November 2005, they reported that 87 people in the survey (around 1 in 12) said they had suffered specific instances of negative treatment, including by insurers and employers. One woman who carried the BRCA1 gene, giving a higher risk of developing breast and ovarian cancer, was denied insurance cover for *all* types of cancer. Those people who had suffered discrimination had not taken any action because they did not know where to go.³³

²⁶ <http://www.advisorybodies.doh.gov.uk/genetics/gaic/Parsons.ppt>

²⁷ <http://www.advisorybodies.doh.gov.uk/genetics/gaic>

²⁸ http://www.informationcommissioner.gov.uk/cms/DocumentUploads/ICO_EmpPracCode.pdf

²⁹ http://europa.eu.int/comm/research/biosociety/pdf/genetic_testing_eur20446.pdf

³⁰ <http://bmj.bmjournals.com/cgi/content/full/327/7419/827-a>

³¹ <http://conventions.coe.int/Treaty/EN/Treaties/Html/164.htm>; and <http://conventions.coe.int/Treaty/Commun/ListeTableauCourt.asp?MA=9&CM=16&CL=ENG>

³² http://europa.eu.int/comm/european_group_ethics/docs/avis18compl-EN.pdf

³³ http://www.eurekalert.org/pub_releases/2005-11/ns-vog110205.php; and <http://www.gdproject.org/whatisit/index.php>

In December 2005, the Australian Government announced that it would be tightening the Disability Discrimination act to prevent genetic discrimination by employers.³⁴

Legislation around the world to prevent genetic discrimination

Some countries, such as Belgium and Austria, have banned genetic discrimination. Others have restricted access to genetic information by insurers and employers (for example, for high-value insurance policies only). The USA has draft national legislation (passed in the Senate but not yet in the House of Representatives) and many States have already banned genetic discrimination.

Conclusions

In 2000, the Government said that 'it would not be acceptable for employers to use the information arising from genetic tests to predict future poor health of potential or existing employees or to exclude people from employment or advancement'.³⁵ Since that time, it has not taken action to prevent the possibility arising. Evidence presented here shows that the potential for genetic discrimination in employment is growing, not receding. New evidence from the USA and Australia is disturbing and necessitates action. The UK Government seems willing to wait until discrimination occurs before taking action. However, it will be much more difficult to reverse decisions by insurers or employers to use genetic tests if discrimination is left to emerge.

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³⁴ http://www.theaustralian.news.com.au/common/story_page/0,5744,17536135%255E2702,00.html

³⁵ http://www.ost.gov.uk/policy/issues/genetic_test.htm