
**Genetic testing and workplace
discrimination**

**TUC evidence to the House of Lords
Science and Technology Committee
inquiry into Genomic Medicine**

29 October 2008

Genetic testing and workplace discrimination

On Wednesday 29 October 2008, the House of Lords Science and Technology Committee will hear evidence on the case for whether the UK needs a law to protect individuals from discrimination by employers and insurers on the grounds of genetic information. In this briefing the TUC will argue the case for such legislation along the lines of the Genetic Information Non-discrimination Act (GINA) passed by the US Senate in April this year.

Genetic Testing – why be concerned?

The 2007 Government Discrimination Law Review consultation, 'A Framework for Fairness; Proposals for a Single Equality Bill for Great Britain' asked the following question of respondents: 'Do you agree that there is no current justification for legislating to prohibit genetic predisposition discrimination?' The Department of Communities and Local Government's consultation paper contested the need for legal protection on the following grounds:

- That there are no actual harms to be addressed
- That legislating might produce collateral harms and
- That there are more appropriate ways to address possible genetic discrimination than through legislation.

In its response to the 2007 consultation the Human Genetics Commission (HGC) disputed the above contentions. In particular, it pointed to evidence from its consultative panel of people affected by genetic conditions that revealed that there is already evidence of discrimination on genetic grounds. An e-mail questionnaire sent to patient support groups for those affected by genetic conditions on behalf of the HGC Monitoring Group in July 2007 found '*a number of cases of serious and distressing discrimination against those with genetic conditions.*' The survey also revealed significant ignorance or misunderstanding

of genetic conditions, in the context of insurance underwriting and more generally in social life.

The danger of allowing genetic testing to flourish without safeguards for individuals lies in the limited reliability and predictability of the tests and the lack of understanding about what they can deliver. As a result, individuals run the risk of being excluded from important financial services such as insurance and employment on the basis of flawed or misinterpreted information. This raises the potential of a genetic underclass being created. Even if the information provided is accurate, or tests become more accurate as technology evolves, there are obvious ethical and moral questions about excluding people from employment opportunities and financial services on the basis of their genetic makeup which is beyond their control.

There are four types of health related genetic test that could be considered useful in the workplace and may be attractive to employers:

- Tests that identify if a person is at risk of genetic illness such as sickle cell anaemia or Huntington's disease
- Tests that identify if an individual is at risk of a common illness such as heart disease or cancer
- Tests to identify if someone is at risk of a work-related disease or susceptible to hazardous chemicals in the workplace that cause cancer or asthma
- Tests to determine if an individual had been exposed to harmful levels of a chemical or radiation at work

Employers may be interested in the above tests in order to exclude workers who may be more susceptible to workplace chemicals from working with them, seeing this as a way to reduce liability and compensation claims. Also to save money by avoiding employing workers who might need considerable time off work or retire early due to ill-health and excluding individuals from health insurance or other employee benefit packages on the basis that they might use these excessively.

Although there is currently little evidence in the UK of employers asking workers to take genetic tests, a survey by the Institute of Directors in 2000, found that 50per cent of respondents were in favour of using genetic tests to identify workers who were at risk from occupational hazards. This support was conditional on the employee being asked for their consent (but in reality given the unequal power relationship between employer and employee, how many employees are likely to refuse consent – and even if they do, is the employer going to draw adverse inferences from such a refusal)?

Additional pressure on employers to make use of genetic testing comes from the marketing of genetic test kits by the bio-tech industry and from the insurance industry and the rising cost of insurance premiums. These factors mean we are likely to see increasing use of genetic testing in the workplace, often by employers with a limited grasp of what the tests can actually deliver.

There is a real concern that employers may see genetic testing as a 'quick fix' solution to enable them to cut costs and reduce health and safety liabilities. However, as the 2003 Genewatch report '*Genetic Testing in the Workplace*' acknowledges, the relationship between genetic makeup and the onset of disease is a complex one. Very many other factors such as lifestyle and diet, also have a major influence on whether genes have an impact on health: *'Currently none of these tests provide an accurate assessment of individual risk. Some tests can be good at identifying who will get a genetic illness, but poor at predicting when symptoms will start or how severe they will be. Tests for common or workplace-related diseases give considerably poorer predictions. Because of the complex interactions between a person's genes and their environment, simply knowing that someone has a particular gene provides very little information about their current or future health. This fact alone means there is little justification for using genetic test results for employment purposes. However there is a real danger that employers might unwittingly or even deliberately, misuse genetic information.'*

Protection from discrimination on grounds of genetic conditions: the case for.

- While there is currently no clear picture of the extent of genetic discrimination in the UK and no systematic attempt to collect such information, there is some evidence of its existence (see the HGC 2007 e-mail survey for example). As a phenomenon it is likely to grow as the technology develops and greater attempts are made to market tests to employers. Discrimination should be tackled pre-emptively, rather than addressing it after the event. If the possibility of genuinely harmful genetic discrimination exists, this should be identified early and suitable provision made before many individuals suffer actual harm.
- There is already considerably more evidence from the United States about the use and abuse of genetic testing. The following examples are all taken from the US (as reported in the Genewatch Report *Genetic Testing in the Workplace*) For example a 2001 lawsuit against a US Railroad company for secretly testing its employees for a rare genetic condition and for threatening an employee who refused testing with dismissal. A case where a social worker lost her job within a week of mentioning that her mother had died of Huntington's disease. A man

who revealed in his job application that he was a carrier of a single gene variation that causes Gaucher's disease was denied employment, even though he was not at all affected by the disease but was a carrier and risked passing it on to his children. A woman notified her employers of a positive test for Huntington's disease and was fired even though she had been promoted in the last 8 months and had received several outstanding performance reviews. A woman who undertook a genetic test because she was experiencing slight breathing difficulties and her brother had previously died from the condition alpha-1 antitrypsin deficiency, tested positively for the condition and received lifesaving treatment as the condition is treatable if detected early. When her employer found out however, she was fired.

- In Australia, the government funded Genetic Discrimination Project is investigating around 100 claims of unfair and negative treatment of people who have had predictive genetic tests, including specific incidents of negative treatment by insurance companies, doctors, employers and family members.
- A British Medical Journal reported case of a teacher in Germany who was refused a permanent teaching position because of a family history of Huntington's disease. This was identified during compulsory medical examination undergone by all applicants to the German civil service. While the medical check found that the teacher was fit to perform her job, it said that there was a 'higher risk' of future absenteeism because of the family link to Huntington's disease.
- There is already evidence that people with genetic conditions are worried about potential discrimination in the fields of employment and insurance and that this may be deterring them from taking medically useful tests which may be of benefit to them. For example, people with genetic conditions in the UK currently face a dilemma over undertaking tests, there is currently a moratorium on the use of predictive genetic test results in insurance until 2014, but is not clear what will happen after that and as HGC Commissioner Michael Harrison has said: *'while the moratorium provides an extended breathing space, it does not solve the problem once and for all. What is known as the 'test now, buy later problem' remains: what will happen to those who are tested but don't buy insurance until after 2014, when the results of those tests may be taken into account.'* A Breakthrough Breast Cancer survey reported to the Genetics and Insurance Committee in 2005 found that in a survey of 71 women (23 with a family history of breast cancer and 48 with no history) a significant proportion might be deterred from taking a genetic test if the results might result in an increase in insurance premiums.

- Currently there is no clear legal framework to prevent the use of genetic testing by employers or insurers to determine who gets insurance or appointed to a job. At the same time there is a growing interest among employers in the use of genetic testing and rapid development and promotion of testing technology.
- Many other countries already acknowledge that genetic discrimination is a cause for concern. Some countries have used data protection law to legislate against genetic discrimination, while others have used equalities legislation. Germany, Slovenia and Spain have provisions based on data protection. In France, discrimination based on genetic characteristics or on predictive genetic tests is prohibited. In Sweden, genetic testing may only take place if it has a medical aim or serves a research purpose. In Finland, employers are prohibited from requiring employees to take part in genetic testing either at the time of recruitment or during employment and employers have no right to find out whether an employee has undergone such testing. In Denmark, restrictions ensure that health checks focus on current health conditions that are relevant to the employee's work. In Austria, genetic screening and the collection, demand, acceptance or any other use of genetic data on employees by employers is explicitly prohibited. There are also restrictions in the Netherlands, Luxembourg and Greece and Italy (*source: Human Genetics Commission response to Discrimination Law Review consultation*). In the United States there is more evidence of genetic discrimination and the Genetic Information Non discrimination Act (GINA) has recently been enacted. This legislation provides protection against genetic discrimination in both the health insurance and employment settings.
- Genetic testing is not a reliable or conclusive predictor of a person's health or ability to do their job. It is unlikely that testing will be scientifically robust in the foreseeable future. An article in the Sunday Times (7 September 2008) illustrated the worrying lack of accuracy and divergent results that can be delivered by genetic testing companies. The researcher used his own DNA and secured genetic test results on this, from three firms that account for the majority of genetic tests in the UK. *'They gave contradictory assessments of the risk I faced of developing illnesses, including Alzheimer's and glaucoma and a confused verdict on my risk of suffering heart problems.....viewing their results proved to be more baffling than enlightening.'* These divergent and even contradictory results raise huge questions about the reliability of the tests currently available. Given these concerns it is surely inappropriate for such tests to be allowed to determine individual's life chances in terms of access to employment and financial services.

- Genetic testing in the workplace and by the insurance industry could reduce effective action to remove potential workplace hazards if employers choose instead to focus on excluding or discriminating against workers and job applicants on the grounds that they are genetically susceptible to workplace hazards or to a future illness that may imply pension and early retirement costs, or have a genetic disorder that may affect their health in future. In this way all workers may lose out as workplace hazards that may otherwise have been removed or reduced, may remain in place.
- The current moratorium on the use of genetic testing in the insurance industry does not provide sufficient protection against future discrimination to those that wish to take a genetic test for health reasons now.

Conclusions and Recommendations

Employers should not have the right to demand that an individual takes a genetic test or reveals a genetic test result as a condition of employment. Employers should not be able to use genetic information to determine employees' terms, conditions, or access to employment benefits. Employees and job seekers who refuse to undertake genetic tests as a condition of employment should be protected from detriment.

New legislation should be enacted to prevent all forms of genetic discrimination and to prohibit employers and insurers from using or accessing individual genetic test results

Within the workplace greater focus should be placed on identifying and reducing workplace hazards to ensure the greater safety of all workers present, rather than on trying to identify workers who are 'vulnerable' to exposure and trying to eliminate these from the workforce.