

GENETIC TESTING IN THE WORKPLACE: Creating a genetic underclass?



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Current laws in the UK allow employers to refuse someone a job on the basis of their genetic test results. Genetic tests for susceptibility to occupational disease are being developed and a few have already been used in workplaces in the USA. However, none of these tests can accurately or reliably predict whether an individual is at risk. It is neither scientifically nor ethically valid to use these tests for employment purposes, but there is a real danger that they could be used inappropriately to discriminate unfairly against employees.

What types of genetic test might be used in the workplace?

A genetic test involves analysing a person's genetic material (their DNA) to see if they possess a 'faulty' gene. DNA can be isolated from a blood sample or a tissue sample obtained by simply scraping the inside of a person's cheek.

Everyone's genes are different. Some of these differences have no impact but, where these differences are significant, they are thought to prevent genes from working properly and so to lead to disease. However, the relationships are far from straightforward. Very many other factors – for example, lifestyle and diet – have a major influence on whether genes have an impact on health.

There are four types of health-related genetic test that might be considered for use in the workplace. These include tests that might identify whether a person:

- was at risk of a **genetic illness**, such as sickle cell anaemia (a blood disease) or Huntington's disease (a nervous system disease);
- was at risk of a **common illness**, such as heart disease or cancer;
- was at risk of a **work-related disease**, or

susceptible to hazardous chemicals in the workplace that cause cancer or asthma;

- had been **exposed to harmful levels of a chemical or radiation** at work.

Currently, none of these tests provide an accurate assessment of individual risk.

Testing for a genetic illness. There are some conditions where possessing a fault in a single gene means that a person will definitely develop a genetic disease. However, even in these 'simple' cases it is not possible to predict exactly when a person will become ill or how severely they will be affected^{1,2}. For example, in the case of Huntington's disease, the age of onset can vary by several decades. Finding that someone had a faulty Huntington's gene would give no indication as to when they might succumb to the disease and be unable to carry out their job.

Testing for risk of a common illness. Tests for susceptibility to common or workplace-related diseases, such as heart disease or cancer, give considerably poorer predictions. There are only a few instances where genes appear to have a strong influence and even these cases are now in doubt. The development of common illnesses is likely to be influenced by very many genes, each one having only a modest impact³. Given this complexity, some researchers have questioned whether we will ever be able to develop genetic tests that provide accurate predictions².

Testing for susceptibility to hazardous chemicals or radiation. People vary in their responses to hazardous chemicals, but this is not because of genetic differences alone. How any particular individual responds depends on many non-genetic factors such as age, weight, gender, diet, and lifestyle (especially smoking)⁴. It is claimed that the

use of these genetic tests will enable those who are most at risk from hazardous chemicals to avoid workplace exposure. However, such tests are more likely to result in genetic discrimination (see below).

Testing for previous exposure to hazardous chemicals or radiation.

Genetic material (DNA) can change over time as a result of workplace exposure to chemicals or radiation. Researchers are using genetic tests to try to find links between different patterns of DNA damage and chemical exposure in the hope that chemical-specific patterns or 'footprints' may emerge. It is hoped that assessing the level of DNA damage will provide an indication of risk of future disease. However, as with the other types of genetic test described above, tests for DNA damage are too imprecise to provide a useful assessment of individual risk⁵.

To date, none of the studies of links between genes and occupational illness have reached a stage where the results could be used to make accurate predictions. Many researchers conclude that the use of current genetic knowledge for employment purposes would be premature and scientifically invalid^{6,7,8}.

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Interpreting (and misinterpreting) genetic risk

A study of a group of workers exposed to benzidine in a manufacturing plant in Germany showed that, of those who went on to develop bladder cancer, a large majority (80%) had a 'slow' form of the *N*-acetyltransferase gene⁹. This might indicate that having a slow form of the gene greatly increases the risk of bladder cancer. However, the data also shows that people with the 'fast' form of the gene are not free from risk. More importantly, over 50% of the people with the slow form of the gene did not develop the disease. Therefore, if a worker tested positive for the slow form of the gene, it would provide them with very little information about their particular risk of cancer from benzidine exposure.

Why would employers want to use genetic tests?

Despite the unreliability of genetic tests, a large number of UK employers have expressed an interest in using them¹⁰. Based on the mistaken belief that genetic tests could provide accurate risk assessments, employers might wish to use such tests to screen job applicants or current employees in order to:

- exclude individuals who may be more susceptible to workplace chemicals from jobs where they are likely to be exposed. Whilst claiming that this would protect workers' health, employers may also see this as a means to reduce liability and compensation claims;
- avoid hiring workers who might need considerable time off work or retire early due to ill-health. This could also cut the costs of sickness benefits;
- exclude individuals from health insurance or other employee benefit schemes on the basis that they might use these benefits excessively;
- monitor the health of employees to assess whether any individuals have been exposed to dangerous levels of chemical hazards. This could result in individuals being removed from their job if they appear to be at greater risk from further exposure or, more positively, could be used as a means of redressing workplace standards;
- exclude some individuals from certain jobs on the grounds that they may pose a threat to others if they develop a predicted illness suddenly.

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Such perceived benefits are likely to be limited, however, and in many cases employers could end up paying for genetic tests that are meaningless or wrong:

The tests are unlikely to provide useful or relevant information. The research evidence shows that most of the claims of links between genes and occupational ill-health are unreliable. Most research results have not been replicated and, in many cases, genes that were thought to be important for some time have since been shown to be irrelevant or of little importance compared to other factors. There is therefore a real danger that employers could base a genetic screening programme on spurious results and exclude the wrong people from the workplace.

No genetic test is 100% accurate. Even if a genetic variation is consistently linked with a higher risk of disease, mistakes can be made when the tests are carried out and any single test may not detect all the variations that can exist in any one gene. Every test carries the possibility of false positives – people wrongly identified as possessing a particular gene variation - and false negatives – people who possess the gene variation but are not detected^{6,11}. Common diseases involve many different genes, but if a battery of tests were carried out, this would become an even bigger problem since the number of false results would multiply¹². There is a danger that large numbers of people could be excluded on the basis of incorrect results.

There are better ways to control risk. Excluding the most susceptible workers has no impact on the hazards that are present in a workplace and there will still be people with some degree of vulnerability left behind. Improving workplace conditions is therefore a far more effective way of reducing occupational illness as it will have an impact on *all* workers. However, some employers might still wish to invest in genetic screening and exclude workers rather than improve safety measures if it proved to be much cheaper.

Screening out susceptible workers may not be cost-effective. One of the proposed benefits of genetic screening in the workplace would be to reduce healthcare and compensation costs associated with occupational disease. However, a screening programme may not necessarily reduce the number of people who become ill. There could also be extra costs for employers from running the programme and providing appropriate care and counselling afterwards. However, these costs could be negligible if genetic testing and follow-up treatment became routine within the NHS so that an employer only had to ask for existing test results.

Although genetic tests will probably be of little benefit, employers are likely to come under increasing pressure to use them from companies selling the tests or from the insurance industry. In September 2002, the Association of British Insurers (ABI) called for “*a radical reform of employers’ liability*” since workplace compensation and pay-out levels have escalated over the past five years^{13,14}. The ABI have recommended that employers are encouraged to invest more in health, safety and risk management procedures. It is possible that employers might be encouraged to hire a ‘less risky’ workforce in order to try to reduce their premiums.

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What are the implications for employees?

It is sometimes suggested that workers might wish to take a genetic test for susceptibility to a workplace-related illness as they would then be able to avoid

the hazardous chemicals or environmental factors that were particularly likely to cause them harm. Similarly, it is argued that workers might support workplace screening since early detection of illness and timely medical treatment could lead to better health outcomes. The issues are sometimes simplified to a matter of consent and it is argued that employees should have free choice as to whether to take a genetic test and subsequently free choice as to whether to take a high risk job¹⁵. However, these arguments are fundamentally flawed since no genetic test is yet able to (or likely to be able to) predict accurately whether an individual is at risk. Nor are workers (or job applicants) often in a position where they can truly exercise freedom of choice.

There are more effective ways of improving employees' health. Genetic tests could result in many - perhaps hundreds - of workers being excluded to prevent one case of a workplace-related disease. The hazards currently under investigation in studies of genetic susceptibility include exposure to sheep dip, pesticides, chemicals used or produced during the manufacture/disposal of PVC plastic (vinyl chloride and dioxins), tobacco smoke and radiation. Improving working conditions for the entire workforce would be a far more effective way of reducing the number of cases of occupational disease. Alternatives such as changing agricultural systems to use less or no harmful chemicals, increasing use of renewable energy, tightening controls on tobacco marketing, and switching to cleaner plastics or alternative materials should also be investigated.

Improving working conditions for the entire workforce would be a far more effective way of reducing the number of cases of occupational disease

Employees may not be able to exercise freedom of choice in relation to genetic tests or high-risk jobs. The imbalance in power between employer and employee makes it difficult to ensure that an employee is giving their voluntary consent to a genetic test. Although existing employees have some legal protection and may benefit from the support of a union, job *applicants* are likely to be particularly vulnerable. They may fear they will not be hired if they refuse to take a test. Refusal to take a genetic test may also be held against an employee if they subsequently develop an occupational illness since they could be said to be responsible for their ill-health on the basis that they were given an earlier opportunity to avoid it.

Taking a genetic test for employment purposes may have wider implications. If an employee were obliged to take a genetic test, there may be repercussions for other members of their family since blood-relatives may also be affected by the same condition. In other contexts, an employee might be required to disclose that they had taken a genetic test for employment purposes and this could be detrimental to other job applications and insurance policies.

Using genetic tests for employment purposes is unethical. A key ethical principle relating to society's use of genetic information is that of respect for human rights and dignity. The UNESCO declaration on the genome and human rights states in Article 6 that: "*No one should be subjected to discrimination based on genetic characteristics if this has the effect of infringing human rights, fundamental freedoms or human dignity*"¹⁶. Excluding people from employment on the basis of their genetic make-up would therefore constitute a violation of this fundamental principle. Choosing people to fit a particular environment according to their genetic-make up, rather than improving the environment for all, has disturbing implications for everyone's rights.

The potential for discrimination

Using genetic tests to identify individuals who might be at risk of ill-health at work is likely to lead to discrimination, the consequences of which could have wider repercussions for public health¹⁷.

If people with genetic faults were to become generally unemployable, they could become part of a 'genetic underclass'. Their health would suffer as a direct consequence of unemployment and living in poverty. This has the potential to reinforce existing health inequalities. People who are more likely to work in industry and be exposed to chemical hazards could suffer more genetic discrimination than the 'white-collar workers' who are never exposed and never submitted to genetic testing. Discrimination against individual workers could therefore become a broader social issue with significant economic and political implications. In addition, since gene variations are not distributed evenly, some populations may be disproportionately affected when these groups may already be stigmatised or disadvantaged. For example, although this has been discontinued, African Americans who wanted to be US Air Force pilots used to be screened for sickle cell trait even though this does not affect their ability to do this job safely.

The fear of discrimination may have far-reaching effects. It may make people reluctant to take genetic tests even though these might sometimes be beneficial to their health. The US Department of Labour found that many women avoid breast cancer gene tests because they believe the results would appear on their records and be made available to employers or insurers¹⁸.

The risk of discrimination may even deter people from taking part in useful medical research. The results from epidemiological research, if replicated and shown to be robust, could be relevant to setting exposure limits, but only if applied to groups of workers and not to individuals. Given that there are potential benefits from research into susceptibility to occupational exposures, it is essential that this research is not stifled through fear of genetic discrimination at work. This type of research relies heavily on the co-operation of workers exposed to occupational hazards and their participation should be encouraged by ensuring adequate safeguards are in place to protect their individual interests.

These fears of discrimination are not unfounded. There have been numerous examples of misuse of genetic information in the USA. In a 1996 survey of individuals who were deemed to be at risk of developing a genetic condition, 200 people had experienced genetic discrimination among the 917 who responded.

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Cases of genetic discrimination in the USA

Case 1: A man who discovered he was a carrier of a single gene variation that causes Gaucher's disease and revealed this fact in his job application was subsequently denied employment¹⁹. He was not at all affected by the condition but risked passing the disease on to his children.

Case 2: A woman in the US who notified her existing employers of a positive test for Huntington's disease was fired from her job. During the previous eight months, she had received a promotion and several outstanding performance reviews¹⁹.

Case 3: A woman who was experiencing slight breathing difficulties went to her doctor for a genetic test because her brother had previously died from alpha-1 antitrypsin deficiency. She tested positive for the condition and received life-saving treatment since the deficiency is treatable if detected early. When her employer found out, she was fired²⁰.

Genetic discrimination at work has the potential to impact on all of us. If employers were to test for risk of common illnesses, it is likely that everyone would be affected since we all probably carry at least one gene variation that predisposes us to cancer. If employers were to test for susceptibility to hazardous exposures, large numbers of the UK workforce would be affected.

Are there adequate legal safeguards to protect the interests of employees?

In the absence of any existing disability, it would not be illegal to use test results to decide whether or not to employ a person

Legislation in the UK

Genetic discrimination at work could result in an individual being denied a job or employee benefits purely on the basis of their genetic make-up. The Disability Discrimination Act 1995 requires employers with fifteen or more employees to make all reasonable adjustments to their premises to provide people with disabilities an opportunity to work. However, the Act only applies to people who are currently disabled or have been in the past. It does not apply to people who have genetic test results that indicate a risk of a future illness but who have not yet developed any symptoms. An employer could therefore ask a job applicant to take a genetic test or reveal the results of a genetic test that they had already taken. In the absence of any existing disability, it would not be illegal to use the results to decide whether or not to employ that person.

Existing employees may be offered some protection from exclusion from work on the basis of genetic tests by the Health and Safety at Work Act of 1974, which makes the removal of a worker from employment an action of last resort. However, this protection is limited by what is 'practicable' for the employer. There is no legislation to protect existing employees from being denied access to employee benefits (e.g. a new pension scheme) on the basis of genetic test results – once hired, an employer may request employees to provide any medical information that is 'job related' and consistent with 'business necessity'.

There is some debate as to whether the The Data Protection Act 1998 would provide adequate protection in the context of genetic information. The Information Commissioner has expressed doubts because, for instance, there is no guidance on how to decide whether an employer's use of genetic test results is fair²¹.

There is no legislation to protect existing employees from being denied access to benefits on the basis of genetic test results

It seems that genetic discrimination could only be prevented by the introduction of new UK legislation²¹. However, the UK Government has stated that, although it would not be appropriate for employers to require or request genetic test results to assess the long-term health of employees or job applicants, "...it might...be appropriate to use specific genetic tests to assess whether an employee's genetic constitution affects his or her susceptibility to specific features of a working environment that do not present any hazard to the majority of people"²². The Government's former advisory committee, the Human Genetics Advisory Commission, has argued that an individual should be required to disclose the results of a genetic test if there is clear evidence that the information it provides is needed to assess either their current ability to do a job safely or their susceptibility to harm from doing a particular job²³. This is worrying because it implies that excluding such workers could be a valid option if alternatives, such as reducing everyone's exposures, are not considered 'reasonably practicable'.

European Legislation

The Council of Europe's Convention on Human Rights and Biomedicine

1997^{24,25} states in Article 11 that: “Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited”.

Article 12 restricts the use of predictive genetic tests to medical contexts and states that: “Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for disease or to detect a genetic predisposition or susceptibility to disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling”.

If the UK were to sign up to the Convention, it would have to become an integral part of UK law, but the UK is amongst 14 out of 45 countries that have not yet signed.

Conclusions

GeneWatch UK concludes that:

No employer should demand that an individual takes a genetic test or reveals a genetic test result as a condition of employment. Nor should employers be allowed to use genetic information to determine an employee’s terms, conditions, privileges or employment benefits.

The TUC has also endorsed these principles and they are consistent with the concerns expressed by many other groups, including the EU Trade Union Confederation, the Human Genetics Commission and the British Medical Association.

The UK Government has endorsed the view that “genetic tests should not be used to predict future health of potential or existing employees or to exclude people from employment” in its response to an early assessment of the implications of genetics for employment²¹. However, its suggestion that it might be appropriate to use genetic tests to assess susceptibility to workplace hazards gives cause for concern.

Many epidemiological researchers conclude that preventative measures to improve workplace conditions are scientifically and ethically far more defensible than excluding workers on the basis of genetic screening. However, research to identify ‘genetically susceptible’ workers is continuing without legislation to ensure that these people are not excluded from employment in future. Therefore:

- New legislation should be introduced to prevent all forms of genetic discrimination and to prohibit employers (and insurers) from using or accessing individual genetic test results.
- The UK Government should ratify and sign the European Convention on Human Rights and Biomedicine without any further delay.
- Greater emphasis should be placed on raising awareness and increasing expertise among employers as to how to reduce workplace exposures instead of trying to identify susceptible workers.

Research to identify ‘genetically susceptible’ workers is continuing without legislation to ensure that these people are not excluded from employment

**This briefing is based on a more detailed GeneWatch UK report by Kristina Staley: “Genetic Testing in the Workplace”.
Price £5 for individuals and £20 for businesses and organisations.**

References

- 1 Evans J.P., Skyznia C., Burke W. (2001) The complexities of predictive genetic testing. *British Medical Journal* **322**, 1052-6.
- 2 Weatherall D.J. (2000) Single gene disorders or complex traits: lessons from the thalasseмии and other monogenic diseases. *British Medical Journal* **321**, 1117-20.
- 3 Zimmern R., Emery J., Richards T. (2001) Putting genetics in perspective. *British Medical Journal* **322**, 1005-6.
- 4 Levy L.S. (2002) Variability and susceptibility to occupational and environmental contaminants. In Institute for Environment and Health, ed. *Variability and susceptibility in human response to occupational exposure to chemicals in the UK (Report R13)*, pp 48-57. Leicester, UK: MRC Institute for Environment and Health.
- 5 Koh D., Seow A., Ong C.N. (1999) Applications of new technology in molecular epidemiology and their relevance to occupational medicine. *Occupational and Environmental Medicine* **56**, 725-9.
- 6 Vineis P., Schulte P.A. (1995) Scientific and ethical aspects of genetic screening of workers for cancer risk: the case of the N-acetyltransferase phenotype. *Journal of Clinical Epidemiology* **48**, 189-97.
- 7 Nebert D.W. et al (2002) NAD(P)H: quinone oxidoreductase (NQO1) polymorphism, exposure to benzene and predisposition to disease: a HuGE review. *Genetics in Medicine* **4**, 62-70.
- 8 Sram R.J. (1998) Effect of glutathione S-transferase M1 polymorphisms on biomarkers of exposure and effects. *Environmental Health Perspectives* **106**, 231-9.
- 9 Thier R. et al (2002) Genetic susceptibility to environmental toxicants: the interface between human and experimental studies in the development of new toxicological concepts. *Toxicology Letters* **127**, 321-7.
- 10 Day, G. (2000) Testing times: Directors' views on health testing at work. London, Institute of Directors.
- 11 Van Damme K. (2000) Genetic testing in the workplace: the scientific aspects. In European Group on Ethics in Science and new technologies to the European Commission, ed. *Genetic testing in the workplace. Proceedings of the Round Table Debate held at the Borchette Centre, Brussels*. pp 3-24.
- 12 Levitt M. (1999) The ethics and impact on behaviour of knowledge about one's own genome. *British Medical Journal* **319**, 1283.
- 13 O'Hara, M. (2002) Insurers act on employers' crisis. *The Guardian*, 6th September.
- 14 ABI. (2002) The ABI calls for fundamental review of workplace compensation. 6th September. London.
- 15 Mohr S., Gochfeld M., Pransky G. (1999) Genetically and medically susceptible workers. *Occupational Medicine: State of the Art Reviews* **14**, 595-611.
- 16 UNESCO (2003) The universal declaration on the human genome and human rights: from theory to practice. <http://unesdoc.unesco.org/images/0012/001229/122990eo.pdf>.
- 17 Zimmern R. and Cook C. (2000) The Nuffield Trust Genetics Scenario Project. Genetics and Health: Policy issues for genetic science and their implications for health and health services. The Stationery Office: London, UK.
- 18 Borger, J. (2000) Who's taking our genes and why? *The Guardian*, 19th September.
- 19 US Department of Labour, Department of Health and Human Services, Equal Employment Opportunity Commission, and Department of Justice (1998) Genetic information and the workplace. The National Human Genome Research Institute.
- 20 Martindale, D. (2001) Pink slip in your genes. *Scientific American*, January.
- 21 Human Genetics Commission (2002) Inside Information. Balancing interests in the use of personal genetic data. Department of Health: London, UK.
- 22 Department of Health (2000) Government Response to HGAC Report on Genetic Testing and Employment.
- 23 Human Genetic Advisory Committee (1999) The implications of genetic testing for employment. London, UK.
- 24 The Human Rights Act 1998. The Stationery Office, London. www.hmsso.gov.uk/acts/acts1998/19980042.htm.
- 25 Convention on Human Rights and Biomedicine. Council of Europe (2001) <http://conventions.coe.int/Treaty/EN/CadreListeTraites.htm>.



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