

Genetics and Employment

Introduction

1 This briefing note of March 2002 stems in large part from a discussion meeting on Genetics, Insurance, Employment and Privacy held on 12 September 2000 and organised by the non-profit Centre for Exploitation of Science and Technology (CEST), which has now closed. This report has been prepared by Dr Alastair Philp, formerly head of the Life Sciences programme at CEST, under the auspices of *MVBio*¹. Several key people were re-contacted to assess material changes since 2000. The issue of private health insurance arranged through employers is not considered here.

Perceptions of how useful genetic tests will be in employment decisions

2 Genetic testing might potentially be used for selection for recruitment, promotion, redundancy or job-transfer. Information about future illnesses and susceptibilities might '*enable employers to identify candidates who are more likely to take significant periods of sick leave*' (and screen them out). However, health is determined by complex interactions of sets of genes with each other, and with multiple environmental and social factors. In almost all cases therefore, **individual genetic tests on currently well people are poor predictors of general health** during working years.

3 Genetic testing might also be used to '*screen out vulnerable people from hazardous work environments*' to which they might be particularly sensitive. However, currently available genetic tests are of little or no benefit in occupational health and pose issues of gender, age and race discrimination. Additionally the basis of health and safety law is to **remove the risk from employees rather than removing the worker from the risk**. '*In 99.9% of cases there will be no case for testing*' since risks should be minimised for all. **The presence of test data also increases the employer's liability** for the wellbeing of the employee (duty of care).

4 A survey by The Recruitment Society in 2000 indicated that few companies plan to introduce genetic testing but many human-resources directors feel the need for more debate. Another survey by the Institute of Directors (also in 2000) suggested that a third of directors felt it was appropriate to test employees for susceptibility to heart disease, and half agreed testing should be used to check for risk of developing a work-related disease. The Recruitment Society have prepared a proposal for a code of practice for genetic testing for employers².

Legal Issues

5 Job applicants and new recruits do not enjoy such strong protection as more established employees³. However **current UK legislation** may offer protection against discrimination due to genetic testing at work.

- **Human rights:** The '*right to respect for private and family life*' in the European Convention on Human Rights (now part of both Scots and English law, following the **Human Rights Act 1998**) means that testing cannot be done without consent, and may mean it cannot be done at all.
- **Sex and race discrimination:** In cases where genetic conditions are sex-linked (e.g. haemophilia) or particularly prevalent in certain ethnic groups (e.g. thalassaemias) then the **Sex Discrimination Act 1975** and the **Race Relations Act 1976** may be relevant.
- **Data protection:** Under the **Data Protection Act 1998** genetic test results are regarded as sensitive data and must be processed according to strict guidelines. '*Unless relevant to the specific features of the job or the workplace, processing genetic data could be unlawful.*'
- **Health and safety:** The **Health and Safety at Work Act 1994** establishes an employer's duty of care for health and safety at work.

¹ See <http://www.mvbio.co.uk>

² Essentially unrevised since 2000; current version available from Steve Huxham at the Recruitment Society

³ See Louise Reohr "Got an illness in the family? In that case you're fired.", *The Independent* 6 Feb 2001

- **Disability discrimination:** The **Disability Discrimination Act 1995** currently applies only if a person '*has or will develop within 12 months a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities*'. Hidden conditions and susceptibilities are not covered.

International Context

6 Testing for employment is prohibited in the US federal government (Executive Order 13145)⁴, and in many US states, but there is no federal law on private employers doing testing. However, the terms of settlement of a court action against BNSF⁵, a rail company, may dissuade other employers and the Bush administration is known to be supportive of proposals to enact legislation in this area. Testing is prohibited in Austria, France and Norway and limited in Netherlands and Denmark⁶. No **international law** in this area is currently binding on the UK. For example the UNESCO universal declaration on the Human Genome and Human Rights⁷ has no legal force and the UK has not yet signed the Council of Europe (COE) Convention on Human Rights and Biomedicine⁸. A COE working group is currently preparing an additional protocol on genetics⁹.

Current UK Government policy on genetics and employment

7 In their July 1999 report 'The implications of genetic testing for employment'¹⁰ the UK Human Genetics Advisory Committee (HGAC) made the following recommendations:

- Individuals have a right not to know their genetic constitution.
- It is unacceptable to screen out workers with a shorter working life (or more sickness absence).
- Testing should only be used '*to ensure [an] employee is not a danger to himself or others, or susceptible to a particular feature of the workplace.*'
- Test results from the past do not need to be disclosed unless they are essential to assess ability to do the job or to determine workplace susceptibility.
- Tests must be accurate, reliable and best practice compliant.
- The Health and Safety Commission should monitor tests.

8 In their response¹¹ the UK government essentially accepted the recommendations but asked the Human Genetics Commission and the Health & Safety Executive to keep the issues under review. The HGAC recommendations and the ABI code of practice on testing for insurance (of note particularly to company health plans) may serve as guidance to the courts in future.

Conclusions

9 Sets of genes interact with each other, and with multiple environmental and social factors, to influence health. Consequently, the information obtained from individual genetic tests is unlikely to be very useful for employment purposes. Current best practice of removing environmental risk from all employees, rather than removing a subset of workers who test adversely, should persist. Human rights law, data protection law and the duty of care implied by a decision to test will make companies think carefully before applying genetic tests. With testing of new recruits, the benefits are still to be demonstrated, unlikely to be many and the costs will, at least initially, be high. Perhaps such testing will first be seen in screening appointees to senior management positions (e.g. as part of a medical exam to check for susceptibility to heart attacks on the job).

⁴ See <http://www.eeoc.gov/docs/guidance-genetic.html#4>

⁵ See <http://edworkforce.house.gov/hearings/107th/eeer/genetic72401/avary.htm>; <http://www.eeoc.gov/press/4-18-01.html>

⁶ See <http://www.eshg.org/Insurance%20background.pdf>

⁷ See <http://www.unesco.org/ibc/en/genome/>

⁸ See <http://conventions.coe.int/treaty/en/Treaties/Html/164.htm>

⁹ See http://www.coe.int/T/E/Communication%5Fand%5FResearch/Press/Themes%5FFiles/Bioethics/e_ProtAddit.asp

¹⁰ See <http://www.doh.gov.uk/hgac/papers/paperg1.htm>

¹¹ See <http://www.doh.gov.uk/genetics/hgacgovresp.htm>