

**The implications of genetic testing for employment / a report by the Human Genetics Advisory Commission.**

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# THE IMPLICATIONS OF GENETIC TESTING FOR EMPLOYMENT

A Report by

The Human Genetics  
Advisory Commission



Human Genetics  
Advisory Commission

July 1999

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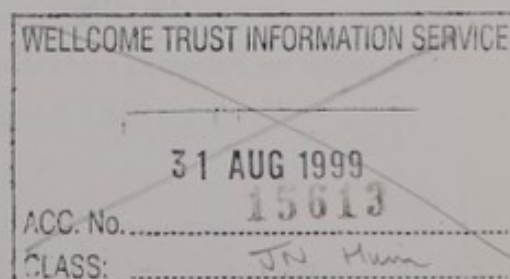
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## FOREWORD

The way in which genetic information is handled and the uses to which it is put are sensitive issues. So far, these issues have not arisen in the area of employment: earlier studies concluded that there was little evidence of systematic use of genetic testing programmes by employers in the UK.

Human genetics is a fast moving field, and employer and employee organisations alike are monitoring developments closely and assessing their implications. HGAC therefore decided that it would be timely to review genetic testing and employment and I have pleasure in presenting our report on this subject.

HGAC has consulted a wide range of organisations and individuals; we are indebted to them for providing information to us so willingly. The report sets out the policy principles we believe should be observed if and when genetic testing in employment becomes a real possibility. We have also recommended that the issues be fully reviewed in five years.

We hope that this report will stimulate wider informed consideration of the employment implications of genetic testing, so that when issues do arise they can be addressed in a balanced and constructive way.

The Baroness O'Neill  
June 1999



## SUMMARY OF CONCLUSIONS AND RECOMMENDATIONS

1. Our enquiries indicate that, with one exception, employers in the UK are not currently using genetic test results. (*Paragraph 3.2*) It will take major developments both in our understanding of common diseases and in genetic testing itself before genetic testing becomes a serious issue for employment practice. (*Paragraph 3.5*)
2. It has been suggested that, as the technology advances, employers may wish to use genetic tests to provide information to predict possible future poor health of their employees. We note in particular the possibility that unfair discrimination might arise if employers use genetic test results for employee selection and conclude that it would not be acceptable for genetic test results to be used to exclude people from employment or advancement on the grounds that they have a predisposition to future ill health. (*Paragraph 3.12*)
3. However, we note that there are situations where it might be appropriate for genetic test results to be used in employment. It is possible that specific genetic tests might be used to detect a condition that may put the employee or others at risk in the workplace. It is also possible that specific genetic tests might be used to assess whether an employee's genetic constitution affects their susceptibility to specific features of a working environment that do not normally present any hazard. Our conclusion therefore is that it would not be in anyone's best interests to ban the use of genetic test results for employment purposes completely. (*Paragraphs 3.14-3.15*)
4. We endorse the conclusions of the Nuffield Council on Bioethics (*paragraph 3.13*) and the Health and Safety Commission's Occupational Health Advisory Committee (*paragraph 3.17*). We note that those with a current disability of genetic origin are protected under the Disability Discrimination Act 1995 in the same way as those with other disabilities. (*Paragraph 2.13*)
5. Although genetic testing is not currently systematically taking place for employment purposes, the scientific and technological barriers to its uptake are likely to be overcome in time. This time period therefore provides an opportunity for measured discourse and agreement (*Paragraph 3.18*).

6. HGAC concludes that if and when genetic testing in employment becomes a real possibility, a common set of policy principles, which would seek to provide appropriate protection to the public in a manner which is least burdensome to employers, should be observed (*Paragraph 3.19*):

- (i) 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;
- (ii) 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 their current ability to perform a job safely or their susceptibility to harm from doing a certain job;
- (iii) 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;
- (iv) any genetic test used for employment purposes must be subject to assured levels of accuracy and reliability, reflecting best practice (in accordance with the principles established by the Advisory Committee on Genetic Testing in its publications<sup>1</sup>). We recommend that any use of genetic testing should be evidence-based and consensual. Results of any test undertaken should always be communicated to the person tested and professional advice should be available. Information about and resulting from the taking of any test should be treated in accordance with Data Protection principles (see paragraphs 8 and 9 below). Furthermore, test results should be carefully interpreted, taking account of how they might be affected by working conditions; and
- (v) if multiple genetic tests were to be performed simultaneously, then each test should meet the standards set out in (ii), (iii) and (iv).

7. We recommend that the Health and Safety Commission should be responsible for monitoring employers' use of genetic tests which detect sensitivity or resistance to workplace hazards; for recommending how and in what circumstances genetic testing might be applied at work as a risk control



measure; and for advising how genetic testing data might be interpreted in a workplace setting. *(Paragraph 3.20)*

8. The handling of genetic test results, which are sensitive personal data, should meet the standards set by the Data Protection principles of fairness and lawfulness. *(Paragraph 2.3)* We note that the proposed Code of Practice being developed by the Data Protection Registrar will clarify the implications of the Data Protection Act (DPA) 1998 for both employer and employee representatives and highlight areas of good practice. *(Paragraph 2.8)*

9. We welcome the Government's proposal to specify the processing of "genetic data" as processing which is assessable under the new DPA and recommend that the Data Protection Registrar (to become the Data Protection Commissioner under the Act) also keeps under review the ways in which employers collect and handle any genetic test results. *(Paragraph 2.9)*

10. The limits of current knowledge about the predictive power of genetic information are not always well understood. We recommend that as part of the Health and Safety Commission's developing strategy for occupational health over the next 10 years, appropriate mechanisms are put in place to involve geneticists, employer and employee representatives and other stakeholders to monitor developments and discuss the implications for employment. *(Paragraph 3.18)*

11. The situation should be monitored and fully reviewed in 5 years time, in light of any further developments. *(Paragraph 3.21)*



## Section 1

### GENETIC TESTING

1.1 The recent rapid advances in genetic analysis and manipulation techniques have made it possible to identify and isolate specific genes involved with particular human diseases. Genetic testing is used to discover variation in genetic material and may help in diagnosis by establishing a cause of symptoms or of a disorder. Some test results may also indicate that a person is at heightened risk of developing a specific disorder in the future. Other test results may show that a person is a carrier of a condition, so that although they will not be affected, they may have children at heightened risk of developing a disorder. A number of terms are in common usage in relation to genetic testing (See Box 1).

1.2 Genetic tests, whether used to test an individual or as part of a screening programme, may be based on analysis of DNA or chromosomes, or on biochemical or haematological screening. The particular test methodology is a matter of technical convenience and does not affect the issues of principle dealt with here.

1.3 Testing in the UK is usually carried out within the NHS, through established medical genetics centres. However, some testing services may be provided by general practitioners, clinicians in private practice, by specialist services such as oncology and haematology and within research settings. Some genetic testing services are also available direct to the public i.e. outside such clinical settings. The UK Advisory Committee on Genetic Testing has recognised a limited role for such services and in 1997 published a Code of Practice<sup>1</sup>. However, the potential exists for difficulties to arise in enforcing national voluntary measures, such as a Code of Practice, in the light of developing e-commerce. Whilst we recognise that there is at present no evidence of this, the Government may wish to monitor the situation.

1.4 At present, most genetic testing in the UK is for one of a limited number of serious genetic disorders, most of which are relatively uncommon, although in aggregate they present a large amount of serious disease. However, possible

<sup>1</sup> *Code of Practice and Guidance on Human Genetic Testing Services Supplied Direct to the Public*: Advisory Committee on Genetic Testing, 1997  
*Report on Genetic Testing for Late Onset Disorders*: Advisory Committee on Genetic Testing, 1998

tests for detecting genes for heightened susceptibility to common diseases are under research, such as those for certain cancers, some forms of heart disease, osteoporosis, dementia and diabetes, and these are likely to be of greater interest to employers. As the results of the Human Genome Project are interpreted, so an increasing range of genetic tests will be developed.

1.5 Technology often referred to as "DNA chip technology" is currently under research. This will allow a single sample to be simultaneously tested for a range of genetic variations. Current laboratory techniques for detecting genetic variations are time-consuming, whereas, a DNA chip - once developed - will speed up the process considerably. Further data analysis would then be necessary to interpret the genetic test results to provide meaningful clinical information.

1.6 This technology may be used to test a single sample for a wide range of unrelated conditions simultaneously. The prospect of easy genetic testing for multiple disease susceptibility raises wider ethical issues. These include the difficulty of giving appropriate information before consent is sought for multi-tests; problems with collecting irrelevant information and the access of third parties to the results of such testing; and questions about the use of the technology to test for characteristics or predispositions without medical significance.

1.7 Although the primary use of genetic test results is for the diagnosis and treatment of an individual, the information obtained also often has implications for other family members. Genetic test results can also provide information about predisposition to future ill health, so are of interest to third parties such as insurers or employers.

1.8 In the context of employment, potential uses of genetic test results might be to provide information about:

- (i) a condition or a predisposition to a condition which might lead to raised levels of absence for sickness;
- (ii) a condition which could put the employee or others at risk in the work place; or
- (iii) heightened sensitivity of an individual to features of a particular work environment.



1.9 The way in which genetic information is handled and the uses to which it is put are sensitive issues; the central concern is to establish the boundary between valid use and abuse effectively.

**BOX 1:**

**Genetic testing** - testing to detect the presence or absence of, or alteration in, a particular gene sequence, chromosome or a gene product, in relation to a genetic disorder.

- **Diagnostic genetic testing** - use of genetic testing in a person with disease symptoms to aid in their diagnosis, treatment and management.
- **Presymptomatic genetic testing** - testing of healthy or asymptomatic individuals to provide information about that individual's future risk of certain specific inherited diseases. Such a test may indicate that the individual has a higher likelihood of developing a disorder. Presymptomatic genetic testing is most frequently offered to those thought to be at high risk of autosomal dominant disorders such as Huntington's disease.
- **Carrier testing** - testing of unaffected individuals to determine whether they are carriers of a gene for a recessively inherited disorder (e.g. cystic fibrosis) and are thus at risk of having an affected child.
- **Susceptibility testing** - testing which provides information about a genetic component in a multifactorial disorder. **Multifactorial disorders** are disorders whose genetic components are not the sole cause, but which work with other, often environmental factors, in determining a disease outcome. Multifactorial disorders include many cardiovascular diseases, most Alzheimer's disease of old age and most forms of diabetes.

*The use of genetic testing for biological monitoring (i.e. as a dosimeter to monitor DNA damage due to environmental effects) is not considered in this report.*

**Genetic screening** - a term used to denote application of genetic tests to populations of people, who individually are not at particularly high risk. In contrast, *genetic testing* of individuals is undertaken when there is some specific prior reason to suspect that the person being tested may be at higher than average risk of carrying the gene change being tested for.

## Section 2

### THE LEGAL CONTEXT - some relevant legislation

2.1 There is at present no UK legislation which directly regulates genetic testing in relation to employment. 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. This section sets out the range of relevant current and impending UK legislation which: (i) protects confidentiality of personal information; (ii) provides protection against discrimination; and (iii) regulates health and safety at work. It also highlights international developments.

#### Confidentiality of personal information

2.2 Confidentiality of medical information, including genetic information, is legally protected in the UK primarily through the common law. Specific legislation has also been enacted to enable individuals to control or to be aware of the use and content of personal information:

- i) The **Access to Medical Reports Act 1988** governs reports made for employment and insurance purposes by the subject's own medical practitioner and requires the permission of the subject for the report to be made. In addition, this Act entitles the subject to the opportunity to see the medical report before it is forwarded to an employer.
- ii) The **Data Protection Act 1998** (DPA) will, when it comes into force (expected in 1999), replace the Data Protection Act 1984 and give effect to the EU Data Protection Directive<sup>2</sup>.

2.3 Under the DPA, there are conditions which must be met before personal data can be processed (a term which encompasses everything from collection to destruction). Data protection considerations impact on the collection, storage and use of genetic test information by employers and the DPA will extend data protection law in the UK for the first time to certain types of manual records. **The handling of genetic test results, which are sensitive personal data, should**

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<sup>2</sup> EU Data Protection Directive (95/46/EC)



meet the standards set by the Data Protection principles of fairness and lawfulness.

2.4 The Act requires that personal data be processed fairly and lawfully. Processing is defined to include obtaining genetic data. The Act stipulates the conditions that must be met for sensitive data to be processed<sup>3</sup>. One such condition is that individuals must be made aware of the purposes for which the information is to be used and of any disclosures to third parties which are intended. This should provide some protection to employees and potential employees.

2.5 A difficulty in the employment context is the imbalance of power between the employer and potential employee. However, the Data Protection Registrar advises that the fact that an individual has consented to the processing of their genetic data does not in itself render the processing fair. It is possible that circumstances where an employer has unreasonably used their dominant position to obtain consent from either an employee or a job applicant would be considered unfair and lead to a breach of the Act.

2.6 Personal data held in compliance with the Act must be adequate, relevant and not excessive in relation to the purpose for which they are held. They must also be accurate and where necessary, kept up to date. These requirements also point to the importance of ensuring that no more is read into genetic test results than can be properly supported by the current state of scientific knowledge. Furthermore, genetic test results may not be kept by an employer for longer than is necessary.

2.7 The new Act will extend an individual's rights to claim compensation for damage and associated distress caused by breaches. Thus, a job applicant who is refused employment because genetic test results are processed unfairly will be able to claim compensation from a potential employer under the terms of the DPA by taking action in court.

2.8 Much of the detail of the 1998 Act will be implemented through subordinate legislation, which will be introduced over the next year and transitional arrangements will apply. In 1998 the Home Office undertook a public consultation process to help inform the preparation of the necessary instruments<sup>4</sup>. This confirmed that, among other things, there was concern about the processing of genetic data. It is important that employers are fully

<sup>3</sup> Schedule 1 part 1 Data Protection Act 1998

<sup>4</sup> *Data Protection Act 1998 subordinate legislation - a consultation paper:* Home Office, August 1998

aware of their obligations under the Act and that individuals are aware of their legal rights. **We note that the proposed Code of Practice being developed by the Data Protection Registrar will clarify the implications of the DPA for both employer and employee representatives and highlight areas of good practice.**

2.9 In addition, given such concern about the purposes for which data relating to genetic testing might be processed, the Home Office is considering whether to specify the processing of "genetic data" as processing which is assessable under the new Act. This would require data controllers of all new processing of genetic data to notify the Data Protection Registrar before the processing begins in order that the Registrar can express a view as to whether the processing is likely to comply with the Act. **We welcome this proposal and recommend that the Data Protection Registrar (to become the Data Protection Commissioner under the Act) also keeps under review the ways in which employers collect and handle any genetic test results.**

### **Protection against discrimination**

2.10 Some fortuitous protection against discrimination by employers on the basis of genetic test results for current conditions may be found in the case of certain conditions which occur primarily in one sex (e.g. haemophilia) or in particular races (e.g. thalassaemia). Discriminating in these cases on the grounds of genetic characteristics may amount to a breach of the **Sex Discrimination Act 1975** or the **Race Relations Act 1976** and any employer or prospective employer would be required to justify the action they were taking.

2.11 Similarly, an employee who has the necessary period of continuous service with an employer (which is now 1 year) and who refuses to undergo a genetic test at the request of his employer would be protected by the **Employment Rights Act 1996** from being dismissed unfairly as a result of that refusal unless an issue of public safety is involved.

2.12 The **Disability Discrimination Act 1995** (DDA) provides a further range of protection. It requires employers with 15 or more employees to make a reasonable adjustment if their premises or working arrangements place a disabled person at a substantial disadvantage compared with people who are not disabled. Adjustments can range from, for example, having training material produced in Braille or large print and using signers for people with hearing impairments, to widening doors for wheelchair access. The DDA outlines a number of factors which would have to be taken into account by a court or tribunal in deciding whether particular steps were reasonable.



2.13 The DDA can offer employees with an adverse genetic test result some protection from discrimination by employers if they are currently disabled and the test was done for a reason relating to that disability. However, the definition of "disability" in the Act does not cover people who have a susceptibility to a future disability. Some have suggested that the definition of "disability" should be amended to ensure that those who are genetically predisposed to some disability are afforded the same level of protection against discrimination as those with existing disabilities. Others point out that extending the definition in this way may not be appropriate within the DDA framework, or any civil rights protection aimed specifically at disabled people. This is because the DDA provides protection in situations far wider than employment (such as the provision of services) and the implications in these areas of altering the definition of "disability" to include people who have no symptoms of disability are unclear. In view of the lack of evidence of any unfair discrimination and uncertainty about what discrimination might occur, some suggest that a better approach might be to legislate separately to prohibit unjustified discrimination on the basis of genetic test results. A specific approach would have the advantage of allowing provisions on confidentiality of test results and proper use of genetic information by employers and others to be thoroughly considered. Nevertheless, careful consideration should be given to whether the definition of "disability" should cover the small number of genetic predispositions which have very high predictiveness or penetrance. This could form part of a later further review of genetic testing and employment.

### **Health and safety at work regulations**

2.14 The **Health and Safety at Work Act 1974** and related regulations (for example, the Management of Health and Safety at Work Regulations 1992 and the Control of Substances Hazardous to Health Regulations 1999) put the onus on employers to ensure, as far as reasonably practicable, the health of all their employees at work. The approach under the Health and Safety at Work Act 1974 is that employers should either prevent exposure to risks or reduce the risks to the health of the worker so far as is reasonably practicable. If residual risks remain, the employer should introduce preventative measures, such as the provision of personal protective equipment and health surveillance. Health surveillance encompasses a range of techniques designed to detect early ill health effects among those exposed to certain hazards e.g. certain chemicals. It is possible that in the future particular genetic tests might be an additional valuable technique. Health and safety regulations require that the removal of the worker from work is an action of last resort - the aim should always be to try to remove the risks.

## International Developments

2.15 There are a number of international measures which control the use of genetic testing. These are currently neither binding on the UK Government, nor make it unlawful for an employer to require an employee either to undertake a genetic test or to reveal the results of previous genetic tests:

- (i) the **UNESCO Declaration on the Human Genome and Human Rights**<sup>5</sup>, provides under Article 6 that no one shall be subjected to discrimination (by which it means unjustified discrimination) based on genetic characteristics if this has the effect of infringing human rights, fundamental freedoms or human dignity. The Declaration has moral, but not legal, force; and
- (ii) the **Council of Europe Convention on Human Rights and Biomedicine**<sup>6</sup> explicitly prohibits any form of discrimination (by which it means unjustified discrimination) on the grounds of genetic heritage (Article 11). In addition, Article 12 provides that, "Tests which are predictive of genetic disease or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes and subject to appropriate genetic counselling". However, it should be noted that this is not an unqualified right, since Article 26 of the Convention allows certain restrictions on the exercise of Article 12's protective provisions. The UK Government has not at present signed the Convention and so its requirements are not currently binding.

2.16 Where the implications of genetic testing for employment have been formally considered by national governments or government sponsored bodies, responses differ from state to state and examples are set out below. Although our enquiries show that there is clearly considerable legislative interest in this issue, they have not revealed the extent to which any of these measures are effective in preventing unfair discrimination.

2.17 There is considerable diversity of approach within the EU, and varying definitions of "genetic testing" and "genetic information" make interpretation complex. In Austria, employers and insurance companies are prohibited by law from collecting, demanding, or using data derived from genetic tests. Danish

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<sup>5</sup> *Universal Declaration on the Human Genome and Human Rights*: UNESCO, November 1997

<sup>6</sup> *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine*: Council of Europe, 1997



legislation aims to ensure that health checks focus on actual/present health conditions and that those conditions are relevant to the employee's work. A working group reporting to the Finnish Ministry of Social Affairs and Health has recommended that employers should not be allowed to subject job seekers to genetic testing during recruitment, or to test employees already hired. French bioethics legislation specifically prohibits access by any third party, notably employers and insurance companies, to information held in databanks and makes it illegal for them to ask individuals to provide such information (this legislation has a five year review clause - due in 1999). In the Netherlands, the Medical Examination Act of 1997 prohibits employers from applying medical criteria to recruitment unless there is an unambiguous health requirement for the job. Genetic testing in the workplace is illegal in Norway. In Spain, legislation makes provisions to distinguish between predictive testing for general health and testing for the protection of workers who are especially sensitive to specific work environments.

2.18 There is also diversity outside the EU. Employers in Japan do not require employees to undergo genetic testing, however they may undertake genetic testing when undiagnosed diseases are being investigated as part of in-work health checks. Although a patchwork of diverse state law already exists in the US, there are no federal laws that directly and comprehensively regulate the gathering or use of genetic information in the workplace. The only federal law that directly addresses the issue of genetic discrimination is the 1996 Health Insurance Portability and Accountability Act. The most likely current source of protection against genetic discrimination in the workplace is provided by laws prohibiting discrimination based on disability. The Americans with Disabilities Act 1990 and similar disability-based anti-discrimination laws, such as the Rehabilitation Act 1973, do not explicitly address genetic information, but they do provide protection against disability related genetic discrimination in the workplace. Recognising that as the science of genetics advances this protection will not be sufficient, President Clinton in 1998 proposed federal legislation barring employers from requiring or requesting disclosure of genetic test results. This proposed legislation has yet to be sponsored by a member of Congress (which needs to happen for the proposal to move to the next stage of becoming law). Various other bills dealing with genetic testing were introduced into Congress last year but none has yet moved past the committee stage.

2.19 We note that genetic testing and employment is a live issue in the US. It seems that much of the tension over genetic testing and employment in the US has arisen because of US reliance on employer-subsidised health insurance. People who either personally, or through their families, represent higher than

average health insurance risks might, it is argued, be discriminated against in employment for this rather than work performance reasons. This is not an issue in the UK at the moment as far as we are aware, although we have learnt through our enquiries that some employers have expressed concern that their insurers may make moves in a similar direction.

2.20 In its response to HGAC's report on insurance and genetic testing<sup>7</sup>, the Government agreed that genetic test results should be disclosed to insurers for use in making underwriting decisions only where the relevance of the test result to the adverse event insured against by a specific type of insurance product has been demonstrated<sup>8</sup>. The Genetics and Insurance Committee (GAIC) was set up in April 1999 to provide independent evaluation of the reliability and actuarial evidence relating to the use of specific genetic test results by insurers. The establishment of this Committee is a useful step towards protecting consumer interests and ensuring that genetic test results are only used in setting insurance premiums when there is scientific evidence that the test is reliable and epidemiological evidence that it is actuarially significant.

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<sup>7</sup> *The Implications of Genetic Testing for Insurance*: HGAC, 1997

<sup>8</sup> *Government Response to the HGAC's Report on the Implications of Genetic Testing for Insurance*: DTI/OST, DH, 1998



## Section 3

### GENETIC TESTING AND EMPLOYMENT

3.1 This section discusses current use of genetic testing by employers, and suggests how in the future employers might wish to make use of genetic testing.

#### Is it happening now ?

3.2 With one exception we found no evidence to suggest that at present employers in the UK are using genetic test results, either during or prior to employment.

3.3 The exception is the UK Ministry of Defence (MoD), which reported that it has a formal central policy covering a specific use of genetic testing in employment. All applicants for air crew training are biochemically screened for sickle cell disease and trait (carrier status. Unusually, carrier status for sickle cell has some risk associated with it). MoD reports that this is a common approach in military aviation medicine, which is designed to protect the individual and others from the potentially catastrophic effects of a sickling crisis provoked by low oxygen pressures in flight. Individuals with sickle cell trait, although generally asymptomatic, can develop symptoms of sickling if exposed to very low oxygen pressures. The real risk of sickle cell trait at altitude remains uncertain<sup>9</sup> and the MoD is currently re-examining its policy on sickle cell trait screening for military air crew training.

3.4 We found no evidence of a trend towards the use of genetic testing for employment purposes elsewhere. A variety of legislative approaches have been taken by European countries (paragraph 2.17), however we have found no evidence of systematic use of genetic tests by European employers. In contrast, a survey conducted in 1989 in the US by the US Congressional Office of Technology Assessment (the most recent documented US evidence of this kind) indicated that a small percentage of employers surveyed were using genetic tests<sup>10</sup>.

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<sup>9</sup> *Aviation Medicine*: Butterworths, 1999. ISBN 07506 32526

<sup>10</sup> *Genetic Monitoring and Screening in the Workplace*: October 1990. OTA-BA-445 NTIS order #PB91-105940

## Will it happen in the future ?

3.5 At present, employers do not make use of genetic test results primarily because most tests currently available are used to confirm diagnosis of current conditions, which are already recorded in medical records. **It will take major developments both in our understanding of common diseases and in genetic testing itself before genetic testing becomes a serious issue for employment practice.** That said, we have heard expert opinion that genetic testing may become relevant to employment in the future, although it is difficult to predict the time scale. Employers already undertake employee health assessments for a variety of reasons (see current practice below). Employers might in the future wish to make use of genetic test results as part of this assessment, either to predict the likely future general health of employees or to obtain information about genetic susceptibility to occupational diseases.

## Health assessment and employment: current practice

3.6 Many employers undertake pre-employment health assessments as part of the employee recruitment procedure. A Health and Safety Executive research study on health surveillance based on a sample of over 1,600 employers reported that just under one third had said that they were carrying out pre-employment assessments<sup>11</sup>.

3.7 In the majority of cases, the assessment consists of either a self-completed questionnaire or a medical examination, and in some cases both. Current practice relies more on questionnaires, which generally cover individual and family history and lifestyle. These questionnaires are subject to ethical guidance for occupational physicians<sup>12</sup>. Questionnaires are usually used to identify whether there is a problem which needs to be followed up. For most employers, the decision as to how far to investigate a potential employee's health will be taken by an occupational physician.

3.8 Employers undertake health assessments for a number of legitimate reasons including:

i) **To meet legal requirements**

According to the type of workplace risk involved, employers undertake regular health surveillance of their employees for the early diagnosis, investigation and treatment of work-related conditions. This surveillance is designed to protect employees from workplace hazards and to comply

<sup>11</sup> *Health Surveillance in Great Britain*: HSE Contract Research Report No. 121/1996

<sup>12</sup> *Guidance on Ethics for Occupational Physicians*: 5th edition Faculty of Occupational Medicine, London 1999



with health and safety law. For example, in certain areas of employment, pre-placement medical examinations are required under the Ionising Radiations Regulations 1985; and employers are required to make eyesight testing available under the Health and Safety (Display Screen Equipment) Regulations 1992.

**ii) To identify employees' work related needs**

Health assessments are also used to help establish an individual's need in relation to their work e.g. fitness for the work activity concerned, the effect of illness on work, rehabilitation following sickness or injury. In the case of disabled employees, such information helps an employer to tailor the job, if necessary, and make any adjustments in accordance with the requirements of the DDA.

**iii) To screen out unsuitable applicants**

An employer may wish to exclude someone from employment where a pre-employment medical examination indicates they are unfit for the post because their existing ill health might make the performance of the proposed job unsafe for the individual or for third parties. However, if the employee or potential employee is defined as disabled in the DDA any employer with 15 or more employees would have to be able to justify doing so and show that no reasonable adjustment could remove or make acceptable any such risk.

**iv) To offer advice on health promotion**

Some employers arrange for employees to be offered health advice. Occupational health services can also advise and help with health lifestyle issues, e.g. diet, exercise and addictions. Some employers also offer some forms of general health checks such as cholesterol, blood pressure and breast cancer screening, usually as part of a benefits package.

**v) To meet company pension and/or insurance scheme requirements**

Some employers offer employees optional company pension schemes and/or health care insurance as part of their remuneration package. These company policies may require information about the health of key personnel or the general work force.

vi) **To limit employer liability**

An employer may wish to seek to detect any pre-existing disorder before an employee commences work, in order to reduce their liability in the event of a future claim of work related disease.

3.9 In a competitive climate, employers will naturally be concerned to manage the cost of employment efficiently. They will wish to minimise absenteeism and are likely to be concerned about the cost of taking on an employee with an existing health problem (subject to the terms of the DDA), especially if it is a chronic disease leading to repeated periods of absence or incapacity. The costs to the employer could include sick pay, health care charges for the individual met by the employer (e.g. private medical insurance costs covered or subsidised by the employer) and lost time for hospital attendance for medical treatments. For example, the latest CBI sickness absence survey, "Missing Out"<sup>13</sup>, showed that in the UK private sector during 1997, on average, 8.4 working days were lost per employee through sickness absence, equating to an estimated £11 billion cost to business. In view of the rapid pace of developments in human genetics and the possible development of cheaper multi-tests, it might become attractive for employers to make use of genetic test results to predict future health and illness in a cost effective way.

### **Potential uses of genetic testing in employment**

3.10 It has been suggested that employers may wish to use genetic tests *to provide information to predict possible future poor health of their employees*. For example, consider a situation where a potential employee tests positive for a late onset condition. Although the individual is asymptomatic at the time, and possession of a particular gene does not predict certainty of ill health or age of onset, an employer may wish not to recruit that individual because he or she may in the future take time off work, or be unable to work to the normal retirement age.

3.11 Clearly, it would be in an employer's interest to seek to minimise costs associated with sick absence and wasted training. Furthermore, companies that offer private health insurance or health care may wish to keep costs down by selecting staff on the basis of future predicted health. A number of employers have commented that as genetic technology becomes more cost effective it is possible that pressure may come from the company's insurers to adopt practices that involve genetic testing. (It was noted in paragraph 2.19 that this issue is driving the genetic testing and employment debate in the US, where there is no

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<sup>13</sup> *Missing Out*: CBI absence and labour turnover survey, 1998



universal health care system and access to health insurance cover is usually through employment).

3.12 As we noted in paragraph 3.5, it will take major developments both in our understanding of common diseases and in genetic testing itself before genetic testing becomes a serious issue for employment practice. The current level of understanding of the implications of most genetic test results for future ill health is quite limited. Since many employees stay in a given job for relatively short times, it would not be reasonable to use this limited ability to predict future health for employment purposes. We note in particular the possibility that unfair discrimination (possibly leading to stigmatisation) might arise if employers use genetic test results for employee selection. **We therefore conclude that it would not be acceptable for genetic test results to be used to exclude people from employment or advancement on the grounds that they have a predisposition to future ill health.**

3.13 We note, however, that there are exceptional circumstances in which the use of genetic tests might be justified. In 1993 the Nuffield Council on Bioethics<sup>14</sup> concluded that:

*genetic screening of employees for increased occupational risks ought only to be contemplated where:-*

- i) there is strong evidence of a clear connection between the working environment and the development of the condition for which genetic testing can be conducted;*
- ii) the condition in question is one which seriously endangers the health of the employee or is one in which an affected employee is likely to present a serious danger to third parties;*
- iii) the condition is one for which the dangers cannot be eliminated or significantly reduced by reasonable measures taken by the employer to modify or respond to the environmental risks.*

We agree with these conclusions for the following reasons.

3.14 Firstly, in the case of a *condition that may put the employee or others at risk in the workplace* and which can be accurately predicted using a genetic test, there is a good case for doing that test. It has been suggested that if it

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<sup>14</sup> *Genetic Screening - Ethical Issues*: Nuffield Council on Bioethics, 1993

were possible for a genetic test to identify, with a high degree of probability, that possession of a particular gene may increase the risk of a heart attack, then it may be in the public interest for airline pilots to be tested for the gene. If tested, the individual might then be offered additional health care monitoring to assess their health status or offered alternative employment. **It would therefore not be in anyone's best interests to ban the use of genetic test results for employment purposes completely.**

3.15 Secondly, specific genetic tests might be used to assess whether an employee's genetic constitution affects their *susceptibility to specific features of a particular type of employment, which do not constitute hazards for other employees*. A good employer might use such genetic test information to protect the well-being of susceptible employees by offering either special protection or alternative work within the organisation.

3.16 There are also concerns that genetic testing may be used to identify individuals who have specific genes that confer resistance to particular workplace hazards and that this information could then, in principle, be used to argue for the relaxation of rules of workplace safety. This approach would breach health and safety regulations.

3.17 In 1995, the Health and Safety Commission's Occupational Health Advisory Committee (OHAC) set up a working group to monitor developments in human genetics that might apply to workplace health and safety. It continues to be that group's view that genetic testing cannot yet add anything reliable to existing workplace health screening and surveillance practices. Given current knowledge, they consider that the existing legal framework for health screening and surveillance, supported by guidance (see paragraph 2.14), provides sufficient protection for workers against risks arising at work. For all normal occupational hazards the aim should be to fit the job to the worker; the exception to which paragraph 3.16 points, is not that of widely shared susceptibility to an occupational hazard. **We endorse the OHAC view and note that those with a current disability of genetic origin are protected under the Disability Discrimination Act 1995 in the same way as those with other disabilities.**

3.18 Although genetic testing is not currently used systematically for employment purposes, the scientific and technological barriers to its uptake are likely to be overcome in time. This interval therefore provides an opportunity for measured discourse and agreement. The limits of current knowledge about the predictive power of genetic information are not always well understood. **We**



recommend that as part of the Health and Safety Commission's developing strategy for occupational health over the next 10 years, appropriate mechanisms are put in place to involve geneticists, employer and employee representatives and other stakeholders to monitor developments in the use of genetic testing and discuss the implications for employment.

3.19 HGAC concludes that if and when genetic testing in employment becomes a real possibility, a common set of policy principles, which would seek to provide appropriate protection to the public in a manner which is least burdensome to employers, should be observed:

- (i) 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;
- (ii) 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;
- (iii) 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;
- (iv) any genetic test used for employment purposes must be subject to assured levels of accuracy and reliability, reflecting best practice (in accordance with the principles established by the Advisory Committee on Genetic Testing in its publications<sup>1</sup>). We recommend that any use of genetic testing should be evidence-based and consensual. Results of any test undertaken should always be communicated to the person tested and professional advice should be available. Information about and resulting from the taking of any test should be treated in accordance with Data Protection principles (see paragraphs 2.3 - 2.9). Furthermore, test results should be carefully interpreted, taking account of how they might be affected by working conditions; and
- (v) if multiple genetic tests were to be performed simultaneously, then each test should meet the standards set out in (ii), (iii) and (iv).

3.20 We recommend that the Health and Safety Commission should be responsible for monitoring employers' use of genetic tests which detect sensitivity or resistance to workplace hazards; for recommending how and in what circumstances genetic testing might be applied at work as a risk control measure; and for advising how genetic testing data might be interpreted in a workplace setting.

3.21 The situation should be monitored and fully reviewed in 5 years time, in light of any further developments.



## MEMBERSHIP OF THE HUMAN GENETICS ADVISORY COMMISSION

\* The Baroness O'Neill

Acting Chair HGAC from 5 February 1999

Principal, Newnham College, Cambridge

Professor Sir Colin Campbell

Chairman of HGAC to 5 February 1999

Vice Chancellor - University of Nottingham

\* Professor Cairns Aitken

Professor-emeritus of Rehabilitation Studies, University of Edinburgh

\* Dr Micheala Aldred

Director - Retinoblastoma Society

\* Professor Martin Bobrow

Professor of Medical Genetics - University of Cambridge

\* Mrs Doris Littlejohn

Chairman of the Employment Working Group

President - Employment Tribunals (Scotland)

Professor Norman Nevin

Chairman - Gene Therapy Advisory Committee

Revd Dr John Polkinghorne

Chairman - Advisory Committee on Genetic Testing

Dr George Poste

Chief Science and Technology Officer - SmithKline Beecham Plc

Ms Moira Stuart

Reporter/presenter - British Broadcasting Corporation

\* Members of the Employment Working Group.

Dr David Wright (Consultant Occupational Physician) was co-opted as a member of this Group.

## TERMS OF REFERENCE OF THE HUMAN GENETICS ADVISORY COMMISSION

- i) to keep under review scientific progress at the frontiers of human genetics and related fields;
- ii) to report on issues arising from new developments in human genetics that can be expected to have wider social, ethical and/or economic consequences, for example in relation to public health, insurance, patents and employment; and
- iii) to advise on ways to build public confidence in, and understanding of, the new genetics.

The terms of reference of the HGAC's Employment Working Group (EWG) were to:

- i) report to the HGAC on the potential value of genetic testing in the workplace and highlight the concerns raised by such developments;
- ii) help raise awareness of the implications of genetic testing amongst employers and employees and help stimulate co-ordinated debate; and
- iii) offer reassurance that wider concerns about this issue are being considered.

In taking forward this work, to build on the Nuffield Council on Bioethics report, Genetic Screening Ethical Issues (1993), and draw on the work of others including the TUC and the HSE, and also to consider how genetic testing may be deployed in the employment field and whether such use is justifiable.



## CONSULTATION

The Working Group conducted its enquiries between July 1998 and May 1999. A broad range of individuals and organisations, including employer and employee representatives, provided information and views both in writing and orally. In addition, a consultative meeting with a range of experts and interested parties was held in October 1998 to explore the issues in further detail.

### Responses to Written Consultation and other contributions

Advisory, Conciliation and Arbitration Service  
Dr John Ballard, Editor, Occupational Health Review  
British Embassies in Athens, Bonn, Brussels, Copenhagen, the Hague, Helsinki, Madrid, Oslo, Paris, Rome, Sweden, Tokyo and Washington  
British Society for Human Genetics  
Professor Roger Brownsword (an editor of the Modern Law Review)  
Confederation of British Industry  
CEST Programmes Limited (a subsidiary of Centre for Exploitation of Science and Technology)  
Christian Action Research & Education  
Civil Aviation Authority  
Confederation of British industry  
Commission for Racial Equality  
Data Protection Registrar  
Department for Education & Employment  
Department of Health  
Department for Trade & Industry  
Employment Lawyers Association  
Engineering Employers Federation  
Equal Opportunities Commission  
Faculty of Occupational Medicine of the Royal College of Physicians  
Genetic Interest Group  
Health & Safety Executive  
Ms Rachel Hurst, Director, Disability Awareness in Action  
Institute of Directors  
Institute for Occupational Medicine, Edinburgh  
Institute of Personnel and Development  
Dr Julian Kinderlerer, University of Sheffield  
London Transport  
Ministry of Defence  
Professor Bernadette Modell, Royal Free Hospital School of Medicine  
National Disability Council  
National Radiological Protection Board  
Dr Darren Shickle, University of Sheffield  
Society of Occupational Medicine  
Trades Union Council  
Ms Charlotte Villiers, University of Glasgow

**Those present at Consultative Meeting held on 19 October 1998**

Ms Angela Edward, Institute of Personnel and Development  
Ms Charlotte Villiers, University of Glasgow  
Mr Colin Adkins, Manufacturing, Science and Finance (MSF) Union  
Dr Elaine Gadd, Department of Health  
Dr John Ballard, Editor, Occupational Health Review, Industrial Relations Services  
Dr Julian Kinderlerer, University of Sheffield  
Dr Sandy Thomas, Nuffield Council on Bioethics  
Mr Graeme Pykett, Confederation of British Industry  
Mr Ian Fulton, Manufacturing, Science and Finance (MSF) Union  
Mr Owen Tudor, Trades Union Congress  
Ms Pippa Gannon, University of Glasgow  
Ms Valerie Ellis, Institution of Professionals, Managers and Specialists

**Speakers:**

Ms Lola Oni, Chairman, National Sickle Cell and Thalassaemia Counsellors' Association  
Professor Roland Wolf, Dundee University

**HGAC Employment Working Group Members:**

Professor Cairns Aitken  
Professor Martin Bobrow  
Mrs Doris Littlejohn (Chairman)  
The Baroness O'Neill

**Observers:**

Mr Eddie Bailey, Health & Safety Executive  
Ms Wendy Simpson, Department for Education & Employment policy on Disability issues

**Others who met the Group**

Mr Eddie Bailey, Health & Safety Executive  
Mr Hardip Begol, Secretary to Disability Rights Task Force  
Dr Peter Graham, Director of Health Directorate, Health & Safety Executive  
Group Captain A N Graham-Cumming, Royal Air Force  
Group Captain John Jones, Royal Air Force  
Mr Roy Kettle, Department for Education & Employment



## GLOSSARY

**Autosomal dominant disorder:** disorders where inheritance of a mutation from one parent only (or arising anew during egg or sperm formation) can be sufficient for the person to be affected. Common dominant disorders in the UK include familial hypercholesterolaemia, Huntington's disease, adult polycystic kidney disease and neurofibromatosis (see below for recessively inherited disorders).

**Genetic disorder:** a condition which is the result of alterations in the genetic make-up of an individual. They may be the direct consequences of defects in single genes (mutations); or in whole chromosomes, parts of which may be lost, duplicated or misplaced; or from the interaction of multiple genes and external factors.

**Genotype:** the genetic make-up of an individual.

**Human Genome Project:** an international scientific collaboration to clone, map and sequence the entire human genome (i.e. 3 billion base pairs; approximately 100,000 genes). It is expected that the complete sequence will be known by about 2003 or possibly sooner.

**Late onset condition:** disorders that normally become symptomatic in adult life although the abnormal gene is present from conception (e.g. Huntington's disease with onset, typically, in early 40s).

**Occupational health:** the study of health problems -associated with the working environment.

**Phenotype:** the appearance (physical, biochemical and physiological ) of an individual which results from the interaction of the environment and the genotype.

**Recessively inherited disorder:** disorders where, for a person to be affected, a mutation has to be inherited from both parents. Such parents are usually unaffected carriers because they only have a single copy of the mutant gene. Common recessive disorders in the UK are cystic fibrosis, haemochromatosis, sickle cell disease and thalassaemia.

**Sickle Cell Disease:** an inherited abnormality of the haemoglobin which causes distortion of the red blood cells (sickling) under low oxygenation conditions. It mostly affects people of African, African/Asian Caribbean, Eastern Mediterranean, Asian and Middle Eastern origin. Individuals who inherit the gene from each parent have sickle cell disease associated with anaemia and sickle cell crises.

**Sickle Cell Trait:** Inheritance of one sickle cell gene (sickle cell trait or carrier status) generally is not associated with any significant medical risks under ordinary conditions.





