



SPO Science Policy

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# **The states of genetic susceptibility in occupational surroundings**

**Questionnaire for genetic effects in biomonitoring  
Importance of technical and ethical aspects.  
A European approach**

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Workplace genetic screening is a sensitive area within occupational health due to a history of misuses, and potential future misuses, with regard to workforce selection. It is discussed, for example, on web sites such as [www.genetic-testing-and-work.be](http://www.genetic-testing-and-work.be) and [www.nuffield.org.uk](http://www.nuffield.org.uk) (from the Nuffield Council on Bioethics).

Genetic testing in the workplace may take the form of screening for heritable susceptibility to exposures and/or disease predisposition, or of monitoring the effects of exposures on genetic material. Both kinds of testing are practised today, with monitoring often forming a part of surveillance programmes. Recently, the Human Genome project has led to very impressive advances in understanding the genetic basis of the individual's risk of disease, which opens new challenges even in the arena of occupational health. However, the validated number of genetic characteristics relevant to workplace genetic screening is not very high. There are great expectations, and it has even been predicted that everyone will carry a gene map, showing all relevant characteristics, in future. The occupational scenario has been set up – for a gene map would give a preview on skills, susceptibilities, risks of diseases, and so on. Fortunately, however, such genetic determinism does not apply to most human characteristics (indeed, virtually all), which are regulated by a number of genes in combination.

The various uses and potential applications of genetic testing give rise to a variety of ethical questions to be covered in future discussion of any workplace application:

- Ownership of data and samples. It has been proposed in Sweden that a third party, e.g. a governmental institution, should be set up to collect and store sensitive information. However, such centralised sensitive-data collectors are not practicable in countries like Germany and France for historical reasons.
- Use of genetic information as part of human integrity. This is probably inevitable, since individual job application is a matter of trust between employer and employee. Beneficial heritable characteristics may be one of several merits of a job applicant. For example, “healthy family history” might be referred to as a qualification.
- Risk of discriminatory practices. This implies that the sifting-out and rejecting of persons with genetic characteristics are close at hand
- Controversies between paternalism and autonomy of decision-making. These are quite clear in cases where an employer requests information on specific health characteristics when selecting workers on the basis of genetic-testing results.
- Protection of confidentiality or anonymity. This may be secured by ensuring that an independent test laboratory performs the test and counsels the applicant.
- Prevention of discrimination and stigmatisation. This is scarcely avoidable, since the primary aim of genetic testing is to select.
- Community considerations. Examples include safety aspects in relation to testing (such as colour blindness); they may become more dominant if safety aspects come to cover behaviours, and so on.
- Scientific quality requirements. These should be laid down by law and ensure the validity of any test.

- Commercialisation of genetic testing. This also poses specific ethical questions, which may be especially relevant to future possibilities of testing employees or insurance applicants. The applicant may be able to test his own genes, with poor counselling as a result.
- Need to consult specialists in genetics. This must be emphasised when considering ideas related to the planning and implementation of biogenetic monitoring and risk assessment.

### **Considerations in situations involving genetic testing**

Respecting the right to work, on the one hand, and the right to be protected against occupational hazards, on the other, speaks for the principle of “first being employed and then tested” rather than that of “first being tested and then employed” (the “if test OK principle”). This, however, may conflict with the interest of the employer. A number of questions to be considered have been posed by Hermeren:

1. How is testing to be timed (before employment or after employment)?
2. Who takes the initiative to test (employer or employee)?
3. What is the purpose of the test (to diminish occupational disease or avoid employment of a person at increased risk)?
4. What is going to be tested (a disease or risk indicators)?
5. Who will be tested (all employees or only a selection of those at risk)?

Questions of the technical quality of the test, the procedures of sampling, processing of samples, storage and analysis and the predictive value of the test should also be answered.

Thorough information about the persons to undergo testing is also a prerequisite. Danish law demands written informed consent with prior information about the purpose of the test, availability of any information derived from the test, correct data management and protection, and the right of the subject to know or not know the test result.

Employers considering genetic testing in employment programmes, and researchers including genetic testing in workplace studies, should be encouraged to consult specialists in biogenetic monitoring and risk assessment.

### **Suggestions for European approach**

In July 2003 the European group of ethics in science and new technologies (EGE) expressed their opinion to the European Commission regarding ethical aspect of genetic testing in the workplace with 19 points. These points are very useful for a European frame, together with existing practice regarding Good Clinical Practice and Data Protection.

### **References**

This paper is derived from Chapter 17 Workplace genetic screening in the textbook: "Practical Ethics in Occupational Health Care" edited by Peter Westerholm John Övretveit Tore Nilstun and published this autumn by Radcliffe.

Directive 2001/20/EC of the European Parliament and of the council of 4 April 2001 on the approximation of the laws, regulations and administrative provisions of the Member States relating to the implementation of good clinical practice in the conduct of clinical trials on medicinal products for human use.

Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data.

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