

Genetic Testing Delegate Guide

This seminar was designed by GeneWatch UK. It aims to raise the future issues that may arise from an expansion in genetic testing to include testing for predispositions to common disorders such as heart disease.

Genetic Tests

Most genetic tests are currently only available through specialist genetic testing services in the NHS, where they are mainly used to diagnose genetic disorders or identify people whose children might inherit such disorders. However, a number of companies are already looking at ways of expanding the market for genetic tests by selling them on the internet, in high street stores, through private GPs or via alternative healthcare providers.

Genetic tests are not regulated – there is no independent assessment of the claims made by commercial companies. This means that people could easily be misled about their health.

People with adverse genetic test results may also be discriminated against on the grounds that they are at higher risk of future illness. Insurers and employers are already interested in using genetic test results to decide premiums or who gets a job. There is currently no law in Britain to prevent employers using genetic test results to decide who gets a job or pension. There is only a voluntary moratorium on the use of most genetic test results by insurers (this ends in 2011).

This seminar is interactive with a role-playing/scenario approach. It is hoped this will help you to think through potential issues and consequences in relation to your own life.

Imaginary Scenario

You will be offered the chance of taking an imaginary genetic test. If you decide to take the test you will be given a letter indicating what genotype you are.

The test identifies only three (imaginary) common genetic variations. You will not learn you have a genetic disorder. Further information about what this might mean for your health will be revealed during the seminar. If you prefer you can choose to open your envelope later, once you have more information. Or you may decide that you prefer not to know.

REFERENCES AND FURTHER INFORMATION

- Some companies are already selling genetic tests that give health advice (for example advice of what to eat and vitamin supplements or medicines to take) based on genetic test results (see, for example: www.nugenix.com).
- Other resources on the issue are available on the GeneWatch web site at <http://www.genewatch.org/HumanGen/default.htm>
- The Government's advisory body on human genetics is the Human Genetics Commission (www.hgc.gov.uk) and reports on some of these issues (e.g. Genetics and Human Behaviour) have also been written by the Nuffield Council of Bioethics (www.nuffieldbioethics.org).