

Predictive Genetic Testing and Insurance

This information sheet has been written for people who are considering having a predictive genetic test for an adult onset condition such as Huntington's disease or inherited cancer syndromes. It aims to provide a brief outline of the current agreements regarding the use of genetic test information by insurers.

There is no legislation in the UK that explicitly prevents discrimination on the basis of genetic differences. However there is a voluntary agreement (called the Concordant and Moratorium) between the Association of British Insurers (ABI) and the Department of Health regarding the use of genetic information, which is in place until November 2011.

According to the agreement:

- Insurers will not use predictive genetic test results to underwrite travel insurance, private medical insurance or any other one-off or annual policy, or for long term care policies
- There are ten commitments on the information to be sought from customers, for example customers will not be asked to undergo a predictive genetic test, disclose a family member's test result or diagnostic genetic test acquired as part of clinical research; or disclose any predictive genetic test results that are made available after their policy has started, for as long as that policy is in place.
- Customers will not be required to disclose results of predictive genetic tests for policies up to £500,000 of life insurance, or £300,000 for income protection insurance, or paying annual benefits of £30,000 for income protection insurance.
- Over these financial limits insurers can only ask about predictive tests that have been approved by Genetics and Insurance Committee (GAIC). The only disease currently on the approved list is Huntington's disease (life insurance only).
- There is a detailed process for resolution of disputes and complaints, which can involve the Financial Ombudsman Service, ABI and GAIC.
- Insurers will continue to use family history information to assess risk and underwrite policies. This practice is not affected by these agreements.
- Insurers may agree to take favourable predictive test results into account, to offset the family history information; when setting the premium (underwriting).

For further information please contact:

- Association of British Insurers (ABI): www.abi.org.uk; 020 7972 1518
- Genetics and Insurance committee (GAIC): www.advisorybodies.doh.gov.uk/genetics/gaic
- Department of Health: 020 792 1518 – to request copy of the *Concordant and Moratorium on Genetics and Insurance*
- Cancerbackup: <http://www.cancerbackup.org.uk>; 0808 800 1234
- NE Thames Regional Genetic Service http://www.ich.ucl.ac.uk/gosh/clinicalservices/Clinical_genetics/Homepage