

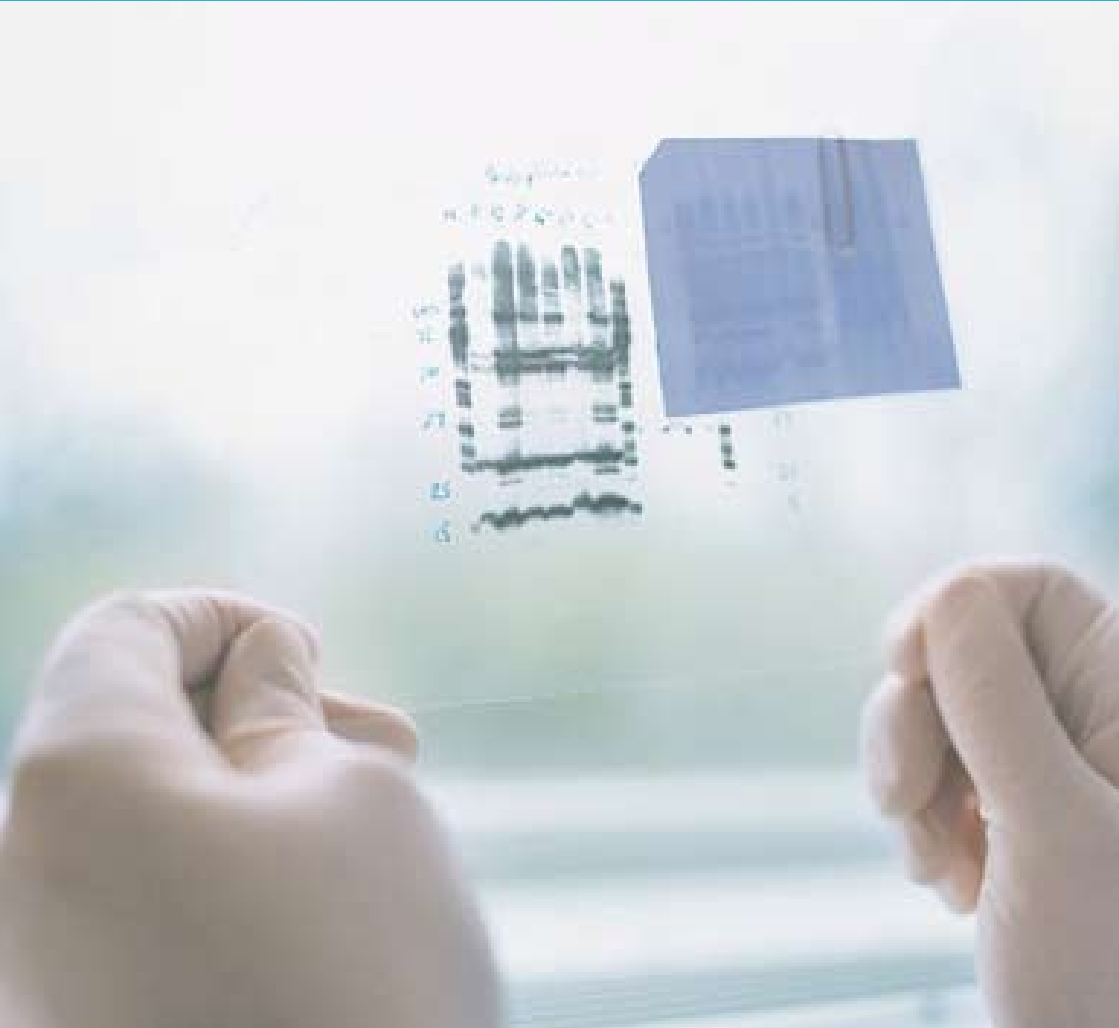


Association of British Insurers

Genetic tests and insurance: what you need to know

A guide for consumers

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1. Introduction

This leaflet explains how insurance companies that are members of the Association of British Insurers (ABI) deal with genetic test results. ABI members sell the vast majority of insurance that is bought in the UK.



The main things you need to know about insurance and genetic tests are that:

- Insurers will not ask you to take a predictive genetic test in order to get insurance;
- You can apply for up to £500,000 for life insurance, £300,000 for critical illness insurance or income protection insurance paying annual benefits of £30,000 without having to tell the insurer the results of any predictive genetic test you have previously taken;
- Above these levels, you only need to tell insurers the results of those predictive genetic tests that an independent Government committee has approved as relevant to insurance companies. The only test that has been approved is for Huntington's Disease, for life insurance worth over £500,000.

2. Insurance and risk

Insurance is all about risk. When you buy insurance, you pay a regular amount ('the premium') and in return, the insurer promises to pay your claim if a particular event happens, such as a serious illness or death.

We can all choose whether or not to buy most types of insurance. Because of this, the price you pay is related to the likelihood of you claiming. If it were not, people in a high-risk group might see insurance as a bargain and buy a lot, whilst people in a low risk group might

see insurance as expensive, and choose not to buy it at all. For example, young drivers as a group have more accidents than older drivers, and so make more claims. As a result, most people think it is reasonable for a 17 year old driver to pay more for their car insurance than a 50 year old driver with the same car.

It is the same with other types of insurance. Those who are more likely to make a claim are asked to pay a higher premium, and sometimes a particular risk is so great that it has to be excluded from the policy.

3. Insurance and medical information

Medical information is important in helping the insurer to decide what premium it is fair to charge you.

To find this out, insurers will ask you questions when you apply for insurance. They may, if you agree, also write to your doctor for more information

relating to your answers. You will normally be asked about your health now, any health problems you have had in the past, and any major health problems in your family. If asked about your health, you must tell the insurer about any symptoms that you have had before, or are experiencing currently.

4. Genetic testing

Genetic test results are a type of medical information. Scientists have identified the genes that can directly cause some rare conditions, such as Huntington's Disease. These conditions are generally caused by a change in a single gene.

Genes involved in the development of more common diseases, such as heart disease, are more likely to be caused by the interaction of several different genes, along with environmental factors like smoking or diet. The interpretation of tests for these genes will be more difficult. For many genetic conditions, doctors can now test your DNA (your 'genetic code') to see if you have inherited normal or faulty copies of the gene from your parents.

Sometimes your doctor may ask you if you want to have a genetic test to confirm that you have a condition, after you have started to show signs suggestive of the illness. This is called a diagnostic genetic test. However, if a particular disease runs in your family, your doctor may offer you a genetic test before you show any symptoms. This is called a predictive genetic test. A genetic



test will tell whether you have inherited the faulty gene linked to that disease. If the test result is normal (negative), then you haven't inherited the faulty gene. If the test result is adverse (positive), then you have got the faulty gene and you may go on to develop the disease.

You may choose to tell the insurer about the result of a predictive genetic test that is in your favour in order to override family history information. Insurers may take this voluntarily disclosed information into account. Each case will be assessed individually.

5. Insurance industry controls

The Association of British Insurers (ABI), the trade association for the UK insurance industry, has operated a code of practice for genetic tests since 1997 – the first such code in the world.

In October 2001, the ABI, in agreement with the Government, announced a moratorium (a voluntary ban) on access by ABI member companies to applicants' predictive genetic test results.

The moratorium means that you can apply for a total of up to £500,000 of life insurance, £300,000 of critical illness insurance, and income protection insurance paying annual benefits of £30,000 without having to tell the insurer the results of any predictive genetic test you have previously taken.

If you want higher amounts than this (in total across all your insurance policies), you will only need to tell the insurer the result of a predictive genetic test, when answering the insurer's questions, where the test has been approved by the Government's independent committee as being relevant to the type of insurance you want. The only test currently approved is for Huntington's Disease, for life insurance over £500,000.



6. Protecting personal information

Insurers are used to dealing with sensitive personal and medical information about their customers – they do it every day. When they are dealing with this information, they have to protect it in line with the law (the Data Protection Act 1998) and with ABI codes.

This also applies to any genetic test information you share with an insurance company. For example, insurers must make sure that staff can only see this information if it is necessary for their job, and it must be locked away securely when not being used, so that other people can't see it. In addition, insurers have to destroy medical evidence when it stops being relevant to them.

7. What to do if things go wrong

Insurance companies aim to provide you with a good service, but recognise that sometimes things can go wrong. If you are not satisfied with the way that an insurance company has dealt with your predictive genetic test result, you should first complain to the company.

If this does not resolve the situation, the insurer will give you, in writing, contact details for the free arbitration service that will look at all underwriting complaints, including decisions, under the code of practice for genetic tests (www.arbitrators.org) and the free Financial Ombudsman Service (www.financial-ombudsman.org.uk) which may look at other underwriting matters.

8. Frequently Asked Questions

Here are the answers to some of the most common questions we are asked about genetics and insurance.

Q. What do you mean by 'genetic test'?

A. A genetic test is a medical test of part of your genetic code. The code is stored in each of the cells in your body. Each cell contains 23 pairs of chromosomes, and the genetic code is written on these chromosomes as 'genes', made up of molecules of the chemical DNA. By 'genetic test', we mean either a test that examines the structure of the chromosomes (a cytogenetic test) or a test that detects abnormal patterns in the DNA of specific genes (a molecular test).

Q. Can an insurance company ask me to take a genetic test for life, critical illness or income protection insurance?

A. No. The ABI's code of practice for genetic tests states that applicants 'will not be asked to, nor be put under any pressure to, undergo a predictive genetic test in order to obtain insurance.'

Q. Do I always need to disclose any genetic test result that I have?

A. No. Under the terms of the moratorium you can apply for a total of up to £500,000 of life insurance, £300,000 of critical illness insurance and income protection insurance paying annual benefits of £30,000 (see section 5) without having to tell the insurer the results of any predictive genetic test you have previously taken. Above these amounts, you will only need to tell the insurer the result of predictive genetic tests, when answering the insurer's questions, where these tests have been approved by the Government's independent committee as being relevant to the type of insurance you want. The only test currently approved is for Huntington's Disease, for life insurance worth over £500,000.

Q. Why does the moratorium have an end date and regular reviews?

A. The moratorium enables consumers to take out substantial amounts of insurance without having to disclose the results of predictive genetic tests. It runs for a set period to give consumers

clarity, while reflecting that geneticists can only see so far ahead. Given the rapid changes in genetic science, the moratorium needs to be reviewed regularly to ensure that the levels of cover remain appropriate for consumer needs and the moratorium reflects the latest understanding of genetic science and medical treatment.

Q. I'm thinking of volunteering for a research study that will include genetic testing. Do I have to tell the insurer about the genetic tests if I apply for insurance in the future?

A. No.

Q. During the moratorium, do I still have to tell insurers that a hereditary (genetic) disease runs in my family?

A. Yes. You must give the insurers any information you know about current or previous illnesses you or your family members have had if it is requested on the application form.

Q. What happens if I take a genetic test and the result is normal (negative), showing that I have not inherited a genetic disease that runs in my family?

A. Many insurance companies will take this information into account in your favour. You may wish to check this with the particular insurance company you apply to.

Q. Do I have to tell my insurer if I take a predictive genetic test after my policy has started?

A. No. Once your policy has started, you do not need to tell your insurer about any predictive genetic test you take later on, for as long as that policy stays in force. This is why it is so important that you tell insurers all relevant information, apart from that covered by the moratorium described above, when you apply. Insurers can refuse to pay a claim later on if you deliberately don't fill in the application form fully and correctly.

Q. One of my relatives has taken a genetic test. Do I need to tell my insurer?

A. No. Under the ABI code of practice for genetic tests insurers cannot use the genetic test result of a relative when looking at an application from you, and vice versa. But if the insurer asks, you will need to tell them about any illnesses that run in your family.

Q. Do insurance companies really know how to interpret genetic test results properly?

A. Yes. In the very small number of cases where an applicant has to tell the insurer a genetic test result, that genetic test will already have been carefully assessed and judged as being relevant by the Government's independent

committee. The interpretation of the individual case will be carried out by senior insurance company staff, in accordance with the ABI code of

practice. They will refer to qualified medical experts and to geneticists for guidance whenever this is needed.

9. Further information

More information about the issues set out in this leaflet is available from the following organisations.

Association of British Insurers (ABI)

51 Gresham Street,
London, EC2V 7HQ
Tel: 020 7600 3333

www.abi.org.uk

ABI is the recognised trade association that represents insurance companies working in the UK. ABI members make up more than 90% of the UK's insurance business.

Genetics and Insurance Committee (GAIC)

GAIC Secretariat, Department of Health,
Skipton House, 80 London Road,
London, SE1 6LH

www.doh.gov.uk/genetics/gaic

GAIC is the Government's independent committee that decides whether particular genetic tests are relevant to insurers.

Genetics Interest Group (GIG)

Unit 4d, Leroy House,
436 Essex Road,
London, N1 3QP
Tel: 020 7704 3141

www.gig.org.uk

GIG is a national alliance of patient organisations with a membership of over 130 charities that support children, families and individuals affected by genetic disorders.

Support groups for particular genetic conditions:

You can ask your doctor if a group exists for the condition you are concerned about. Information is also available from GIG.

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