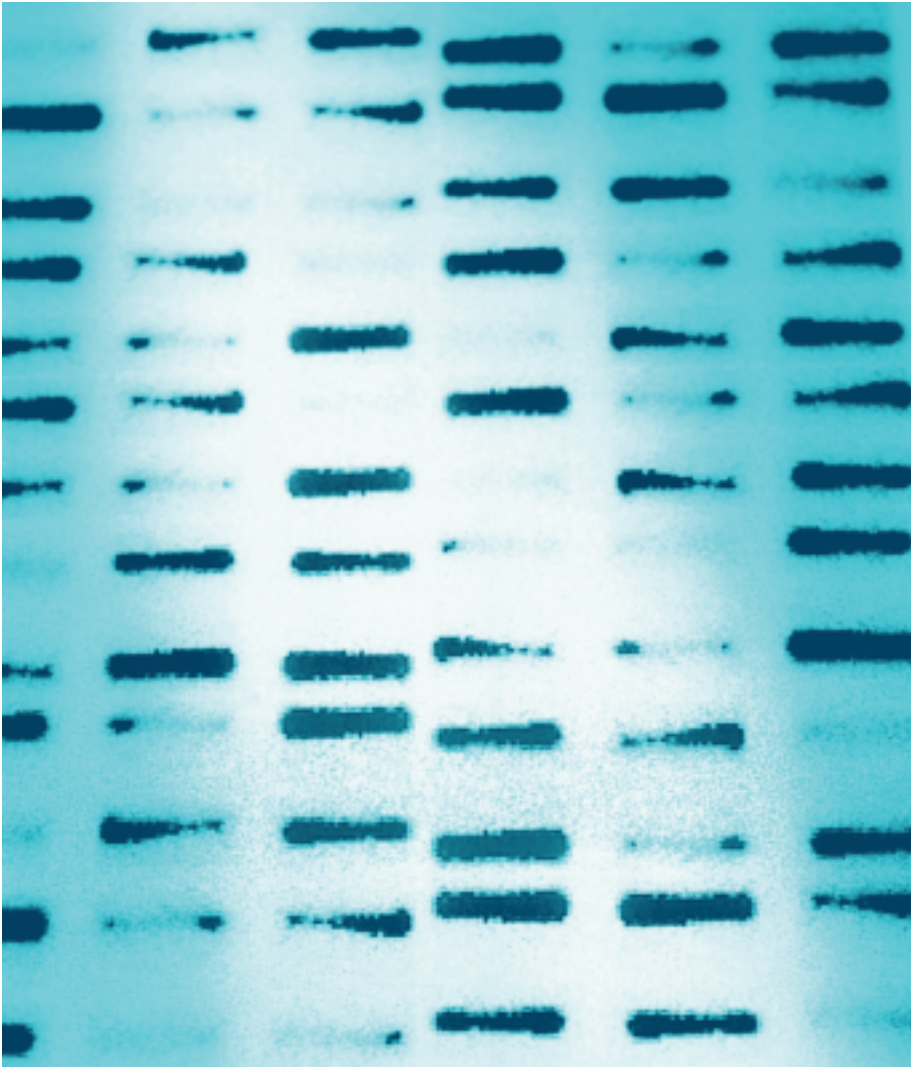




Association of British Insurers

June 2005

INSURANCE AND GENETIC TESTS WHAT YOU NEED TO KNOW





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1 Introduction

Are you thinking about taking a genetic test? Do you want to know how this could affect your insurance? This leaflet tells you the key things you need to know.

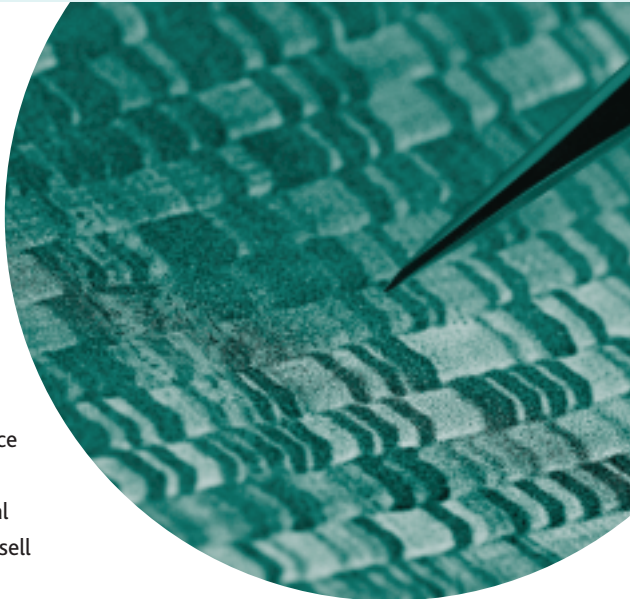
This leaflet explains how those insurance companies that are members of the Association of British Insurers (ABI) deal with genetic test results. ABI members sell the vast majority of insurance that is bought in the UK.

A list of frequently asked questions can be found at the end of the leaflet.

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

- Insurers will not ask you to take a genetic test in order to get insurance;
- Until November 2011, you can apply for a total of up to £500,000 of life insurance, £300,000 of critical illness insurance, and £30,000 annual benefit of income protection insurance 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 genetic tests that an independent Government committee has approved as relevant to insurance companies. You will be told which ones these are when you apply. You can also get the current list from ABI.

* Section 4 on page 4 explains what a 'predictive genetic test' is.





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 (e.g. serious illness or death) happens. If the insurer is to stay in business, it will need to charge enough in premiums to cover all of its claims and its costs. It will also need to keep its premiums competitive to attract and keep its customers.

If you claim, the amount the insurer pays you will be much larger than the total premiums you have paid them. The difference comes from the premiums of

people who do not claim, and from any income the insurance company gets by investing all the premiums it receives.

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. On rare occasions, the risks are high enough to mean that insurance cannot be provided at all.



3 Insurance and medical information

There are many different types of insurance. Medical information, including genetic information, is only important for certain types. Those where it is most important are:

- life insurance - which pays out on your death;
- health insurance, and in particular:
 - critical illness insurance – which pays a lump sum if you get one of a list of serious illnesses; and
 - income protection insurance – which pays an income if you can't work because you are either ill or injured.

Information about your health is very important to life and health insurers in deciding what premium it is fair to charge you. To find this out, insurers will ask you questions on your application form. 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 immediate family (your parents, brothers and sisters). 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. Over the past few years, scientists have identified the genes which can directly cause some rare conditions – for example, Huntington’s Disease. These conditions are generally caused by a change in a single gene. For some of these 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.

At the moment, there are only a few such tests. However, it is likely that more genetic tests for diseases caused by a single faulty gene will be developed in future. It may also be that genes involved in the development of more common diseases, such as heart disease, will be discovered. These diseases are more likely to be caused by the interaction of several different genes, along with environmental effects (such as smoking or diet), and the interpretation of tests for these genes will be more difficult.

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

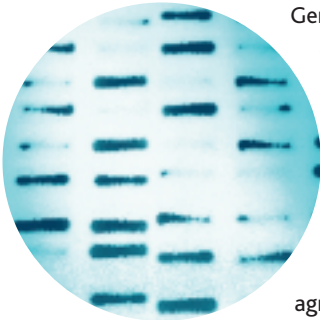
before you show any symptoms. This is called a **predictive genetic test**. This test will tell whether you have inherited the faulty gene linked to that disease. If the test result is normal (negative), then you haven’t inherited the faulty gene. If the test result is adverse (positive), then you have got the faulty gene and you *may* go on to develop the disease. In future, some people may be offered predictive tests for more common conditions, even though the condition does not run in their family.

For some conditions, an adverse genetic test result means you are almost certain to develop the disease. For others, an adverse result means only that you may be more likely to develop the disease. This is because other factors, such as your diet, lifestyle and environment, interact with your genes to determine what happens to you.

If the result of a genetic test indicates that you are at higher risk of getting a disease, it may be relevant to applications for some types of insurance. Genetic test information is not relevant to motor, household or private medical insurance, for example, but may be relevant to life and some health insurance. However, even if it is relevant, an adverse genetic test result does not necessarily mean that an insurer will charge you a higher premium, or turn you down. Each case will be judged on its merits.

5 Insurance industry controls

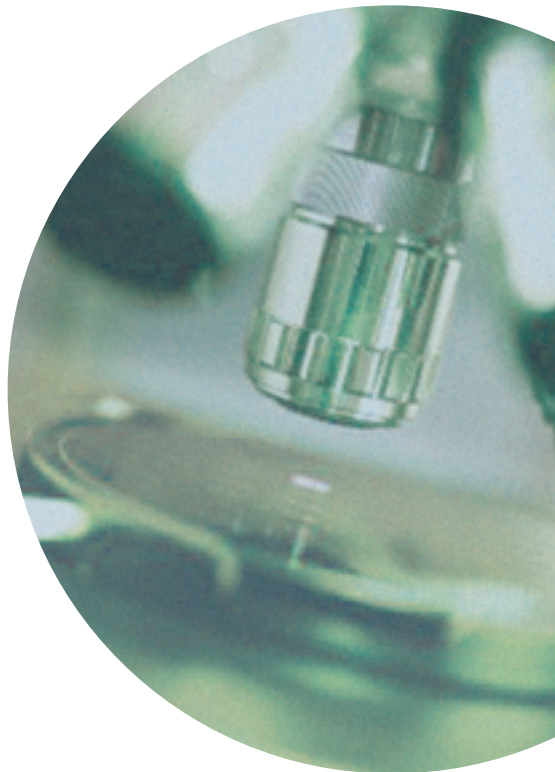
The Association of British Insurers (ABI), the trade association for the UK insurance industry, has operated a Genetic Testing



Code of Practice since 1997 – the first such Code in the world. In October 2001, the ABI, in agreement with the Government, announced

a moratorium (i.e. a voluntary ban) on access by ABI member companies to applicants' predictive genetic test results. The moratorium, which was renewed in 2005 means that until November 2011, you can apply for a total of up to £500,000 of life insurance, £300,000 of critical illness and £30,000 annual benefit of income protection insurance without having to tell the insurer the results of any predictive genetic test you have previously taken. If you want higher amounts than this (totalled 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 Genetics and

Insurance Committee (GAIC) as being relevant to the type of insurance you want. You will be told which tests these are when you apply for insurance. You can also find out from ABI which tests have been approved (you can look on our website, or ring us). Our contact details are at the end of this leaflet.





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 genetic test result, you should first complain to the company. If this does not resolve the situation, you should then contact the ABI (address below). In the unlikely event that your complaint is not resolved by the ABI, you can contact the Government's Genetics and Insurance Committee (GAIC). Finally, there is an independent appeals tribunal which can also look at individual complaints that are not resolved at an earlier stage. Contact details are in section 9 below.



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?

A. No. The ABI's Code of Practice on Genetic Testing states that 'applicants must not be asked to undergo a 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 five year moratorium renewed in March 2005, you can

apply for a total of up to £500,000 of life insurance, and £300,000 of certain types of health insurance (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 Genetics and Insurance Committee (GAIC) as being relevant to the type of insurance you want.

Q. Which genetic tests are insurers interested in the results of?

A. Those that indicate that you are at a higher risk of developing a particular disease.

Q. This moratorium lasts until November 2011. What then?

A. The moratorium was introduced to provide a breathing space, during which the industry, the Government, and other interested groups can discuss and agree on a sensible long term solution. These discussions are ongoing, and the outcome is not clear as yet.

Q. I'm thinking of volunteering for a research study that will include genetic testing. Will this affect any applications for insurance that I make in future?

A. No. The insurance industry is not interested in the results of predictive



genetic tests taken as part of a research study. Insurers are only interested in the results of genetic tests taken as part of your medical care, and then, only if the test has been approved by GAIC.

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. 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 genetic test after I've bought my insurance?

A. No – not for existing policies. Once your insurance policy has started, you do not need to tell the insurer about the results of any 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.

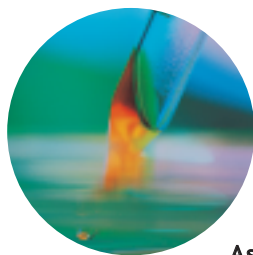
Q. One of my relatives has taken a genetic test. Do I need to tell my insurer?

A. No. The ABI Code forbids insurers from using 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 Government-appointed experts (GAIC – see above). 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. 51 Gresham Street, London EC2V 7HQ. Tel: 020 7600 3333. This leaflet was produced by the ABI, and the controls it describes apply only to insurers that are ABI members. The list of genetic tests currently approved by the Government (see GAIC's entry below) as suitable for insurance use is on the ABI website (www.abi.org.uk/Public/Consumer/Codes/disclosure.asp). You can also find out by ringing the ABI consumer information helpline (020 7216 7455) or by contacting GAIC.

Genetics and Insurance Committee (GAIC).

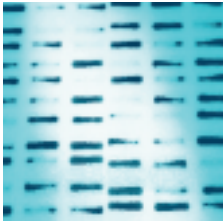
GAIC Secretariat, Department of Health, Skipton House, 80 London Road, London SE1 6LH. (www.advisorybodies.doh.gov.uk/genetics/gaic/index.htm). GAIC is the Government Committee that decides whether particular genetic tests are relevant to insurers.

Genetic Interest Group. Unit 4d, Leroy House, 436 Essex Road, London N1 3QP. Tel: 020 7704 3141. (www.gig.org.uk).

GiG is an umbrella group that represents the interests of all those affected by, or at risk of, 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 (see above).

The ABI is the trade association for the UK insurance industry. We represent over 400 insurance companies, that together provide over 95% of insurance in the UK. ABI provides services to its members, and represents their interests to the Government and to regulators and other bodies.



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