



# Consumer Guide: Code on Genetic Testing and Insurance

July 2023

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### **The UK insurance and long-term savings market and the ABI**

*The Association of British Insurers is the voice of the UK's world-leading insurance and long-term savings industry. A productive and inclusive sector, our industry supports towns and cities across Britain in building back a balanced and innovative economy, employing over 300,000 individuals in high-skilled, lifelong careers, two-thirds of which are outside of London.*

*The UK insurance and long-term savings industry manages investments of over £1.9 trillion, contributes over £16bn in taxes to the Government and supports communities across the UK by enabling trade, risk-taking, investment and innovation. We are also a global success story, the largest in Europe and the fourth largest in the world.*

*The ABI represents over 200 member companies, including most household names and specialist providers, giving peace of mind to customers across the UK.*

# Consumer Guide: Code on Genetic Testing and Insurance

July 2023

This refreshed guide serves three main purposes:

- To help people understand the Code.
- To help people to respond to the 2023 Call for Evidence.
- Provide users of the Code with the information they need to use it effectively.

*The Code on Genetic Testing and Insurance (the Code) aims to provide reassurance to the public about how and whether genetic testing could affect their access to life, critical illness, and income protection insurance products in the UK. It also ensures that insurers have the minimum information needed to accurately price insurance premiums for all consumers.*

## Section 1: Introduction to insurance

### What is insurance?

Insurance is a legal agreement between the insurer and the insured. When you buy an insurance policy you make regular payments, known as premiums, to the insurer. If you need to make a claim your insurer will pay out based on what is covered by your policy. Many insurers also support their policyholders to take actions that promote resilience, such as promoting healthy behaviours and access to preventative health services, to reduce the likelihood that you will need to claim. These measures benefit both the insurer and the insured, as well as wider society.

### What is the purpose of insurance?

The social purpose that underpins insurance is to protect people against the impact of risks they face. Life, health and protection insurers protect customers against the impact of health risks. In other words, they can provide you with access to services and treatment to keep you fit and healthy and pay-out if you get ill to help you to manage your finances. This means insurers have an interest in keeping people well as it reduces the number of claims. It is worth noting that the proportion of claims that are paid out remains very high. In 2021, the insurance industry paid out 98% of life insurance, income protection and critical illness insurance claims. The average pay out on life insurance policies was £80,485 and on income protection policies it was £23,380.

### What is involved when an insurer is calculating my premium and level of cover?

When you look to buy insurance, insurers will use a range of information to calculate the premium and level of cover they are able to offer. The level of premium and cover are based on the likelihood of you needing to make a claim against your policy and how much they will need to pay to you if you make a claim. Most policyholders are accepted at

a 'basic' or 'standard' premium rate. However, if there is a higher risk that you will need to claim than the basic premium allows, then insurers have a range of options:

- still offer standard terms
- increase the premium
- exclude certain conditions or costs from the policy (i.e., reduce the level of cover)
- in extreme cases they may not offer cover

Each insurer will determine their own approach to pricing and the level of cover. This is why consumers are offered different prices and levels of cover by different insurers across all types of insurance. Insurers do these calculations to ensure they offer a fair and equitable premium, and they can make insurance widely accessible.

## **Section 2: An overview of Genetic Testing and Insurance**

### **What is a genetic test?**

Genetic testing – sometimes called genomic testing – finds changes in genes that can cause health problems. It is mainly used to diagnose rare and inherited health conditions and some cancers, but it is increasingly used to understand the population's health. Under this Code on Genetic Testing and Insurance, a genetic test refers to a test that looks for a particular gene variant. This is regardless of whether the test was carried out as part of a single-gene test, a panel, or up to the level of whole genome sequencing.

You may be offered a genetic test by a healthcare professional because:

- your doctor thinks you might have a health condition caused by a change to one or more of your genes.
- to help confirm or exclude a diagnosis where you have symptoms or signs of a medical condition.
- someone in your family has a health condition that's caused by changes to genes.
- some of your close relatives have had a particular type of cancer that could be inherited.
- you or your partner have a health condition that could be passed on to your children.

A genetic test can:

- help to diagnose a rare health condition.
- help you understand whether an inherited health condition may affect you, your child or another family member, and help you make reproductive choices.
- show if you are at higher risk of getting certain health conditions, including some types of cancer.
- guide doctors in deciding what medicine or treatment to give you.
- guide doctors on whether you're able to join a clinical trial<sup>1</sup>

For the purposes of insurance, genetic tests are grouped into two categories – predictive and diagnostic.

**Predictive:** If a particular genetic condition runs in your family, but you show no signs or symptoms of the condition, a predictive genetic test predicts your future risk of developing the condition. This may be for a gene that is suspected of

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<sup>1</sup> <https://www.nhs.uk/conditions/genetic-and-genomic-testing/>

causing a condition or for a gene that is suspected of causing a high incidence of a common condition in your family.

Diagnostic: If you are showing signs or symptoms that could be related to a particular genetic condition, a diagnostic genetic test confirms or rules out whether you have the condition.

## Genetic testing and insurance

The ABI and its members support progress in genomic medicine. Insurers recognise that the development of genetic testing is crucial for informing the diagnosis, prevention, and treatment of health conditions. This has significant societal value for all including insurers and their customers. It can also minimise and reduce claims, which can have a positive impact on insurance premiums and improve access to insurance.

The government also recognises that it is important for insurers to access appropriate health information with relevant consumer consent. This allows insurers to effectively assess the level of risk to be covered and accurately price premiums. Asking for relevant information such as details about an individual's family history and socioeconomic data, such as health and lifestyle, enables insurers to understand the range of risks they are insuring.

This means that when applying for some types of insurance, an insurance company may ask you to provide health and medical information about you and your family. This includes telling insurers if you have an existing health condition that has been diagnosed by genetic testing. This is so that they can determine what level of cover they can provide and at what cost.

## How does the Code on Genetic Testing and Insurance work?

The information that insurers will and will not ask you to provide in relation to genetic testing has been formalised in the [‘Code on Genetic Testing and Insurance’](#).

If you are applying for insurance from a company that has signed up to the Code, they have committed to the following:

- To never require or pressure you to have a predictive or diagnostic genetic test, under any circumstances.
- To not ask for, or take into account, the result of a predictive genetic test if you are applying for insurance. The only exception is if you are applying for life insurance where the value (i.e. the pre-decided amount payable when an insured event happens) is over £500,000 and you have had a predictive genetic test for Huntington's Disease.

For predictive tests:

- You do not need to tell the insurance company about a predictive genetic test (including for Huntington's Disease) if:
  - you have had the test as part of scientific research (for further information see FAQs 4 and 5);
  - your relative or your spouse has had the test; or
  - you have the test after you have taken out insurance.
- If you have a predictive genetic test that is in your favour, you can choose to tell the insurance company as this might help your application. An example is if you have had a test that shows you haven't inherited a condition that runs in your family. You should visit the company's website, or contact them directly, to find out whether and how they take negative predictive genetic results into account to improve the terms of insurance in your favour.

- You can ask an insurance company about how the result of a predictive genetic test result has contributed to a decision made about your application. If you don't think the company has acted according to the Code, the Code also explains how you can make a complaint.

For diagnostic tests:

- The Code recognises that a diagnostic genetic test is the same as any other diagnostic medical test, such as a blood test or scan, that is taken if you are showing signs or symptoms of a condition. This means you might need to tell the insurance company about the results of a diagnostic genetic test when you apply for insurance. You might be asked for this information as part of the application form, or it may be included in your medical report if the insurance company asks to see it as part of your application, and the GP thinks the test is relevant.

Further information can be found in Section 3 FAQs.

### Which insurance products could be affected by a genetic test result?

Under the Code, ABI member insurers who provide one-off or annual policies such as travel insurance, motor insurance or private medical insurance will not ask for the results of a predictive genetic test result, in any circumstance. As a result, the agreement in this Code only applies to how genetic information is treated by insurers who provide life, critical illness and income protection insurance.

**Life insurance** can provide a cash lump sum in the event of your death, or if you become diagnosed with a critical illness. By paying a monthly premium or a lump sum to your insurer for life cover, you can safeguard your loved ones from financial hardship if you die or suffer from one of a list of illnesses. The money can be put towards funeral costs, payment of a mortgage, debts, or your family's living expenses.

**Critical illness** cover gives you protection to minimise the financial impact of certain illnesses and medical conditions of a specific severity. Your cover will provide you with a tax-free lump sum cash payment which can be used to help you and your family. For example, it could help you pay off your mortgage, pay for treatment to help you recover or pay your household bills.

**Income Protection** helps support you financially if you fall out of work because of injury or illness. This type of insurance protects against loss of earnings and covers most illnesses that leave you unable to work. Income Protection Insurance only covers you if you're unable to work due to illness or injury – it does not pay out if you are made redundant.

### What is the role of the Association of British Insurers (ABI)?

The Association of British Insurers (ABI) is a trade association representing the voice of the UK's insurance and long-term savings industry. The ABI's membership includes over 200 companies, including most household names and specialist providers in the insurance sector. Compliance with the [Code on Genetic Testing and Insurance](#) is a condition of ABI membership. In addition, insurers not within ABI membership can publicly state their intention to comply with the Code and report relevant compliance data to the ABI. On an annual basis, each insurer who has signed up to the Code will confirm to the ABI that they continue to comply with the Code. You can see a full list of insurance companies who have signed up to the Code on the [ABI website](#).

This information is shared in a publicly available annual report by the Government and the ABI. Under the terms of the Code, insurers must report any complaints to the ABI and set out if and how a complaint is resolved. In 2021, there was one complaint reported about the use of genetic test results by an insurance company and it was resolved. Insurers must also report on the number of policies sold in that year where genetic test results were

relevant.

## How are changes made to the Code?

The Code sets out very strict criteria for amendments to the list of relevant predictive genetic tests. The ABI is required to submit a written application to Government (and also to publish this application on their website), including evidence to demonstrate that:

- the condition is well understood and carries an increased risk of significant morbidity and/or mortality;
- a predictive genetic test is available, which meets certain standards, and
- there is a high risk that individuals buying insurance based on information that insurers do not know would have an effect on insurance markets and impact individual premiums for other consumers, if not addressed.

This would then be followed by a stakeholder engagement process, and independent peer review of the application by a panel of experts. Government would be required to communicate a decision within 6-12 months of publication of the application, whereupon a revised version of the Code would be published by the ABI and Government.

The ABI and its members currently do not have plans to seek new exceptions to be applied to the financial limits within the Code.

## Huntington's Disease:

### Why is Huntington's disease the only condition that needs to be disclosed?

The predictive test for Huntington's disease is included in the Code given the condition is inherited in a clear and measurable manner and there is a high probability that those with the gene variant will develop the condition. Huntington's disease has a wide impact on a person's functional abilities and usually results in movement, thinking (cognitive) and psychiatric disorders.

However, this test only needs to be disclosed to insurers if the applicant is applying for life insurance at a value of over £500,000.

### Does the Code deter people from taking the predictive genetic test for Huntington's disease?

The Code should not act as a deterrent as it is important for people who have a family history of Huntington's Disease to take actions that support their wellbeing. It is important to ensure that people are aware that disclosure is only required for life insurance cover worth £500,000 or over.

For context, in 2021 only 4% of all life insurance premiums were valued at £500,000 or more. Given Huntington's is a rare disease the likelihood of someone in that 4% having Huntington's is extremely small.

Additionally, people have to disclose to an insurer if someone in their family has Huntington's Disease irrespective of whether they have taken a genetic test or not, meaning that any perceived benefit of not taking the test from an insurance perspective is limited, and if the test is negative, it could reduce the individual's premium.

### If I have a negative predictive genetic test result for Huntington's Disease, but still have to disclose the condition as part of my family history, will I still face a higher premium?

The Code does not prevent insurance companies from using family history to calculate insurance premiums as it is

considered to be an independent risk factor, separate from genetic test results. Therefore, it is possible that higher premiums may be charged. If you are unsure about what to tell your insurer, there are specialised insurance brokers who can help to identify different insurance companies or products for those with complex and pre-existing health conditions.

### How does this differ to genetic tests for other diseases?

The only difference is that a positive predictive genetic test for Huntington's Disease must be disclosed if you are applying for life insurance cover worth £500,000 or more.

Further information can be found in Section 3 FAQs.

## Section 3: FAQs

### 1. What genetic test results do I need to share with an insurer?

A core consumer protection in the Code is that insurers will not require or pressure any applicant to undertake a predictive or diagnostic genetic test to obtain insurance.

To date, there is only one predictive genetic test that insurers can request a customer to disclose when they are applying for insurance - the predictive genetic test for Huntington's disease. Insurers can only ask for this if the customer is applying for life insurance cover over £500,000.

Here are three examples to demonstrate how the Code functions in relation to predictive tests:

#### **Example A: I have taken a predictive test and the results are negative.**

You do not need to disclose this information to an insurer.

On the other hand, if you have a predictive genetic test result that is in your favour, you can choose to tell the insurance company as this might help your application. An example is if you have had a test which shows that you have not inherited the genetic variant for a condition that runs in your family. Individual insurance companies are required to publish information to make clear how they will use such test results to inform their underwriting decisions. The vast majority of insurers will take into account the results of a voluntarily disclosed genetic test result, provided it is from a reputable source. This often allows them to make a more accurate decision with a better outcome for the applicant.

When filling in an application form, it should usually be clear where you can tell an insurer about a genetic test that shows you have not inherited a risk identified in your family – this may just be a section for extra notes. If it is not clear, you should call or email an insurer about this information.

#### **Example B: I have taken a predictive test and the results are positive, but I am asymptomatic, and all other tests are normal.**

You do not need to disclose the result of this predictive genetic test to the insurance company, unless it is a predictive genetic test for Huntington's disease for life insurance and the cover is for over £500,000.



## **Example C: I have taken a predictive test and the results are positive, and this has led to further diagnostic tests that show I have a disease.**

You do not need to disclose the predictive test result. However:

- if an insurer asks whether you have suffered from a specific medical condition, then you need to disclose your diagnosis regardless of whether there is any genetic component or not; and
- if you have further diagnostic tests such as an MRI, or start to take medicine to prevent or treat a disease, these will likely have to be disclosed to an insurer.

The purpose of the Code is to reassure people that they can take a genetic test without it having a direct impact on pricing, and therefore they should not decide against taking a test for the sake of insurance.

### **2. Do I need to tell an insurer about a diagnostic genetic test result?**

Yes, if an insurer requests information about diagnostic genetic test results.

The Government and the ABI recognise that certain types of health information can be relevant when pricing risk, and therefore insurers can request relevant health information from applicants. In the same way as a blood test or MRI scan, genetic testing can be used to confirm diagnoses of ill health. Insurers can request the results of diagnostic tests, including diagnostic genetic tests, and may use these results to inform their decision about an application. Insurers agree that they will maintain stringent procedures for seeking access to such information as set out in the Access to Medical Reports Act 1988 and by [ABI guidance](#), created in consultation with the ICO and the British Medical Association.

### **3. What happens if I tell an insurer about a genetic test and it turns out to be predictive, not diagnostic?**

If a consumer discloses a predictive genetic test result that does not need to be disclosed, insurance companies should ignore it.

Additionally, consumers are protected by the [Consumer Insurance \(Disclosure and Representations\) Act, 2012](#), which gives you legal protection if you unknowingly give incorrect or incomplete information to your insurer. This means your insurer will not be able to decline a claim on the grounds of non-disclosure unless you carelessly or deliberately lied or misrepresented your circumstances.

Finally, if consumers are unsure about what to tell their insurer, there are specialised insurance brokers who can help to identify different insurance companies or products for those with complex and pre-existing health conditions.

### **4. Do I have to disclose any predictive genetic test results I receive through as part of a research study?**

No. You will not need to disclose any predictive genetic test results from taking part in a research study, and an insurer will not ask you to disclose these results. Even if you do (unintentionally) disclose this information to an insurer, the test result would be ignored by insurance companies and your application would be assessed as if this had not been disclosed.

### **5. I have been diagnosed with a condition, and through a research study I received a genetic finding which is relevant to my diagnosis. Do I need to tell insurers about the genetic result when disclosing my diagnosis as part of the application process?**

No. You only need to answer the questions in the application form. If the form asks you if you have suffered from a

specific medical condition, then you need to disclose this regardless of whether there is any genetic component or not. However, you do not need to disclose the genetic test result even though this may be associated with your diagnosis.

For example, if you had previously been diagnosed with breast cancer, and through a research study you discover you have a mutation in the BRCA1/2 genes, you do not need to mention the genetic test result when disclosing your previous diagnosis.

## **6. My insurance premiums are higher due to my family history; how does the Code protect me?**

The code allows insurance companies to calculate insurance premiums using family history as it is considered to be an independent risk factor, separate to genetic test results. Therefore, it is possible that higher premiums may be charged.

The Code also commits insurance companies to not require or pressure any applicant to undertake a predictive or diagnostic genetic test to obtain insurance regardless of their family history.

## **7. How is compliance with the Code monitored?**

Compliance with the Code is a condition of ABI membership. All insurers that have signed up to the Code confirm to the ABI via their Chief Underwriter or Head of Compliance that they comply with the Code on an annual basis. Compliance with the Code is monitored through insurers reporting data to the ABI on the number of genetic test results disclosed by applicants and the total number of complaints received about breaches of the commitments.

The government committed to publishing this compliance data in annual reports. [The latest published data is from 2020](#). The 2021 data will be published in 2023.