



# Annual Report: Code on Genetic Testing and Insurance

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

*The ABI is the voice of the UK's world-leading insurance and long-term savings industry, which is the largest sector in Europe and the third largest in the world. We represent more than 300 firms within our membership, including most household names and specialist providers, providing peace of mind to customers across the UK.*

*We are a purpose-led organisation: Together, driving change to protect and build a thriving society. On behalf of our members, we work closely with the UK's governments, HM Treasury, regulators, consumer organisations and NGOs, to help ensure that our industry is trusted by customers, is invested in people and planet, and can drive growth and innovation through an effective market.*

*A productive and inclusive sector, our industry supports towns and cities across Britain in building a balanced and innovative economy, employing over 300,000 individuals in high-skilled, lifelong careers, two-thirds of whom are outside of London. Our members manage investments of £1.4 trillion, contribute £18.5 billion in taxes to the Government and support communities and businesses across the UK.*

# Annual Report: Code on Genetic Testing and Insurance

## 1 Background

### 1.1 The Code on Genetic Testing and Insurance

The [Code on Genetic Testing and Insurance](#) (the Code) was published in October 2018 and replaced the Concordat and Moratorium on Genetics and Insurance (which had been in place since 2005 and 2001, respectively).

The Code aims to provide reassurance to the public about how and whether genetic testing could affect their access to insurance products in the UK. It also enables insurers to put in place appropriate risk management so that insurance is accessible to a broad spectrum of consumers and offers fair value.

Commitment 1 of [the Code](#):

*Insurers will always treat applicants fairly. They will not require or pressure any applicant to undertake a predictive or diagnostic genetic test in order to obtain insurance. Insurers will not treat any applicant differently if they have had a predictive genetic test, except as detailed [in the rest of the Code].*

Commitments 4-6 of [the Code](#) state:

*4. Where insurers ask an applicant to disclose the result of a predictive genetic test in the limited circumstances described in Commitment 2, they will not impose disproportionate terms, conditions or exclusions related to that result.*

*5. Insurers will provide all applicants with clear information before an application for insurance cover is completed explaining:*

- a. What they will and will not have to disclose regarding genetic test results, in accordance with this Code.*
- b. How their insurance decision may be affected if an applicant decides voluntarily to disclose any favourable predictive genetic test result.*

*6. If a predictive genetic test result is given to an insurer by the applicant, either accidentally or voluntarily, an insurer may take it into account if it is to the applicant's benefit. For instance, if a predictive genetic test result was disclosed which ruled out a risk which was otherwise suggested by family history, the insurer may take this into account to offer more favourable terms. If the result is unfavourable to the applicant, the insurer will ignore the result unless Commitment 2 applies.*

The Code is an agreement between the Government and the Association of British Insurers (ABI). The Code is a condition of ABI membership and all insurers that are signed up to the Code will:

- never require or pressure any applicant to undertake a predictive or diagnostic genetic test.
- only consider the result of a predictive genetic test for a very small minority of cases.

To date, there is only one predictive test for which insurers can request disclosure of results. This is a predictive genetic test for Huntington's disease, and limited to applications for life insurance cover in which the total sum assured is over the financial limit of £500,000.

Commitment 2 of [the Code](#):

*Insurers will only ask applicants to disclose the result of a predictive genetic test and take the result of this test into account, for conditions that have been approved as being relevant under this Code, and for policies above the following financial limits:*

- a. Life insurance – £500,000 (per person)*
- b. Critical illness insurance - £300,000 (per person)*
- c. Income protection - £30,000 (per annum)*

*The list of approved relevant predictive genetic tests is given in Appendix I. The current list only includes a predictive genetic test for Huntington's disease, in applications for life insurance cover which totals over the financial limit of £500,000.*

Any predictive genetic test result obtained exclusively in the context of scientific research does not need to be disclosed to an insurer, regardless of the test or the level of cover.

To support stakeholder understanding of the Code, the ABI updated the accompanying [Consumer Guide on Genetic Testing and Insurance](#) in 2023. This complements the existing Q&A available [on the ABI's website](#).

## **1.2 The UK insurance and long-term savings market and the 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 300 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 also sign up to the Code and report relevant compliance data to the ABI. You can see a full list of insurance companies that have signed up to the Code [on the ABI website](#).

On an annual basis, each insurer who has signed up to the Code will confirm to the ABI that they comply with the Code. In addition, under the terms of the Code, insurers must report any complaints to the ABI and set out if and how a complaint is resolved.

Insurers who transact life, critical illness or income protection insurance will also nominate at least one appropriately trained genetics underwriter (NGU).



Commitment 8 of [the Code](#):

*Insurers who transact life, critical illness or income protection insurance will nominate at least one appropriately trained genetics underwriter (NGU), who is responsible for all matters relating to genetic information and the operation of this Code. The full duties and responsibilities of the NGU are given in Appendix II [of the Code]. The number of NGUs should be proportionate to the scale of the business.*

### 1.3 Annual reporting and three-yearly reviews

The Code is open-ended with no expiry date. Under the Code, the ABI and the Government have both agreed to publish an Annual Report to provide a commentary on the state of the insurance market, developments in genomic medicine, and compliance with the Code.

In addition, a joint review of the Code will be conducted every three years to ensure the Code remains fit for purpose and keeps pace with developments in genetic testing and genomics. The Government and the ABI agree they must maintain a well-informed shared understanding of the current state of genomic technologies and the potential impacts on the insurance market.

## 2 Genetic Testing and Insurance

### 2.1 The purpose of insurance

The social purpose that underpins insurance is to protect people against the risks they face. Whether that is the risk of damage to a property or a car, or the risk of illness, injury and loss of life. Insurers help to protect individuals and families against the impact of such risks.


In 2023, the insurance industry paid out 97.4% of life insurance, income protection and critical illness insurance claims, totalling £7.34 billion and equivalent to £20.1 million a day – the highest on record.

The average pay out on life insurance policies was £80,403 and it was £22,270 on income protection policies.

### 2.2 Why genetics is relevant to insurance

The ABI and its members support progress in genetic and genomic medicine. Insurers recognise that the development of genetic testing is crucial for informing the diagnosis, prevention and treatment of ill health. This has significant societal value, and it is good for insurers and their customers. Prevention minimises the risk of ill-health and reduces claims which can have a positive impact on insurance premiums and improve overall 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 customers to provide health and medical information about themselves and their family. This includes telling insurers if they have a 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.

The increased use of genetic testing could lead to individuals having more information about their likelihood of developing disease in the future. The Code means that insurers do not ask for predictive genetic test results that would highlight whether someone has greater risk of ill-health. Insurers undertake to disregard such tests if they are disclosed, unless they mitigate the potential risk.

As more people take predictive tests, the industry needs to be able to monitor whether this changes the insurance they buy. If a material information asymmetry develops, whereby individual policyholders understand their risk in a way insurers are not allowed to, this could result in inaccurate pricing of insurance cover for individuals. In the longer term, this could lead to ‘anti-selection’ where a greater proportion of those with an increased risk purchase insurance and the insurer is unable to price this risk into their premiums. If this happens it could lead to unsustainable risk management, rising insurance premiums and reduced availability of insurance.

The Government and insurance industry recognise that the public have concerns about the use of genomic information by insurance companies and, more generally, how their data are used. The Government and ABI continue to work with patient, consumer and health professional representatives to achieve a well-balanced relationship regarding the fair and transparent use of genetic test results in the limited instances when they are used in insurance.

### 2.3 Differences between insurance products

The Code applies to all insurance products but, in practice, is only relevant to those products which use health information to assess risk:

- protection insurance - life, income protection and critical illness, and
- health insurance - private medical insurance.

Travel insurers currently have little interest in genetic information as the health information they use is to assess the risk of emergency medical treatment when travelling, rather than long-term health risks. Currently, it is only health and protection products that are concerned about the potential for anti-selection arising from genetic testing.

This is because protection products are long term and pay out lump sums or regular amounts of money. They are generally only underwritten (i.e., the risk is assessed) at the start of the policy, with terms that mean customers can claim at any point from day one to as long as 50 years or more.

For these products, assessing longer-term risk is critical for insurers to set the right price for premiums and terms of the policy at the outset. Once customers have agreed to the policy terms offered by the insurer, for most policies, the insurer cannot alter the terms of cover for the duration of the policy. Therefore, an inability to accurately predict future health risks could lead to unsustainable risk management, rising insurance premiums and reduced availability of insurance.

For health insurers, Private Medical Insurance, which is annually renewable, pays for healthcare rather than paying financial sums. The current inability of health insurers to use genetic information could lead to insurers paying large claims they are not able to predict and price for in their premiums. That could lead to insurers excluding certain treatments in new policies if they feel the Code prevents them from being able to assess the risk of providing cover.

### 3 Reporting Data

#### 3.1 Companies compliant with the Code

Compliance with the Code and the adoption of the Commitments in the Code is a condition of membership for all ABI members. Most insurance companies who are not members of the ABI have also signed up to the terms of the Code. The list of all of those companies who are compliant with the Code can be found [here](#).

#### 3.2 Compliance data

Under the terms of the Code, the ABI commits to publishing data that demonstrates how insurers are complying with the terms of the Code. This transparency aims to provide confidence in how the Code is working.

The table below sets out the total number of diagnostic, predictive and unknown tests reported to insurance companies. Under the terms of the Code, insurers can ask for, and use, the diagnostic test results reported to them. Insurers do not request results of predictive tests and will ignore these tests when they should not have been disclosed, therefore these will not impact on how an insurer underwrites that customer's policy.

Currently, the only times insurers may use predictive tests are when a voluntarily provided test result mitigates an adverse family history - usually to the benefit of the consumer by way of a lower premium - or for an accepted test over the financial limits (currently only a predictive genetic test for Huntington's disease in applications for life insurance cover which total over £500,000). The data does not break down the number of predictive genetic test results to show how many were used to benefit the consumer by mitigating an adverse family history.

The table has previously shown a consistent increase in the number of both predictive and diagnostic tests over time, reflecting the increasing number of genetic tests taking place in the UK. This year's data shows a slight decrease on the previous year's data, whilst still higher than all years prior to this.

Number of Genetic Test	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023
Predictive Results	1,410	1,571	1,878	1,700	1,458	1,336	1,407	1,754	1,937	2,123	2,118	2,255	2,401	2,282
Diagnostic Results	1,474	1,718	1,980	2,035	1,879	1,753	1,827	2,061	2,779	3,476	3,502	4,076	5,169	4,690
Other / Do Not Know	134	340	326	314	331	328	360	310	338	388	368	485	508	481
<b>Total</b>	<b>3,246</b>	<b>3,629</b>	<b>4,184</b>	<b>4,049</b>	<b>3,668</b>	<b>3,417</b>	<b>3,594</b>	<b>4,125</b>	<b>5,054</b>	<b>5,987</b>	<b>5,988</b>	<b>6,816</b>	<b>8,078</b>	<b>7,453</b>



### 3.3 How the financial limits apply to policies

The graphs on the next pages show the distribution of life, income protection and critical illness insurance policies written against their respective financial limits within the Code. These graphs only look at new insurance policies which started that year, rather than all existing policies. This is because it is only at the start of the policy that the financial limit is applied and so this provides a more accurate picture and helps identify any emerging trends.

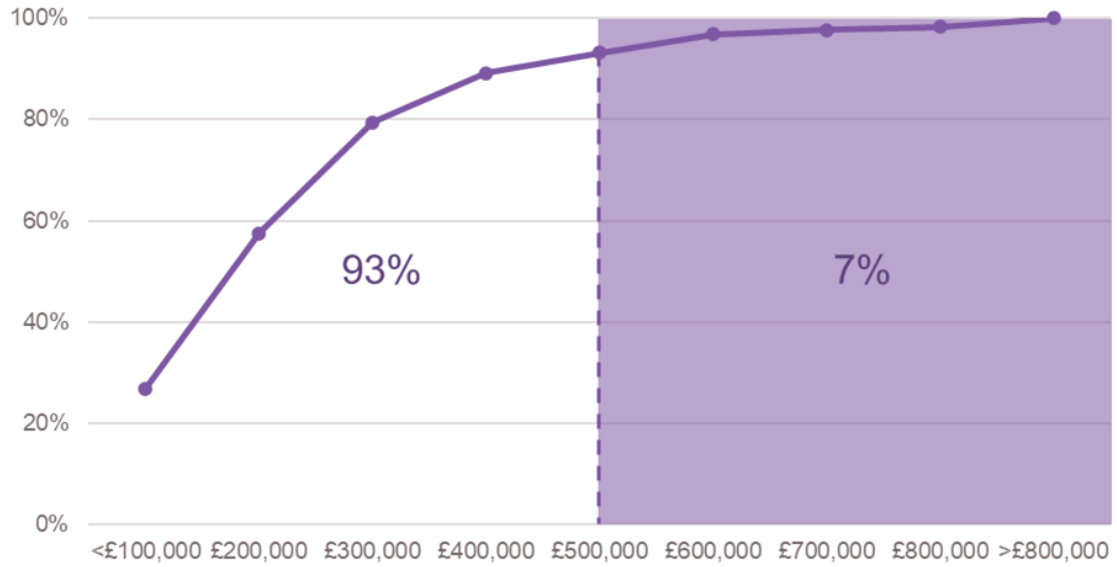
Although it is important to monitor the number of policies underneath these limits, in practice, only the life insurance limit is currently relevant. This is because Huntington's disease for life insurance is the only exception within the Code. The other limits would only become relevant in the event of a new exception coming into force for these products.

In 2023, 93% of life insurance policies fell below the financial limit of £500,000; 86% of income protection policies fell within the limit of £30,000 (per annum); and, 99% of critical illness policies and 95% of accelerated critical illness policies fell under the limit of £300,000.

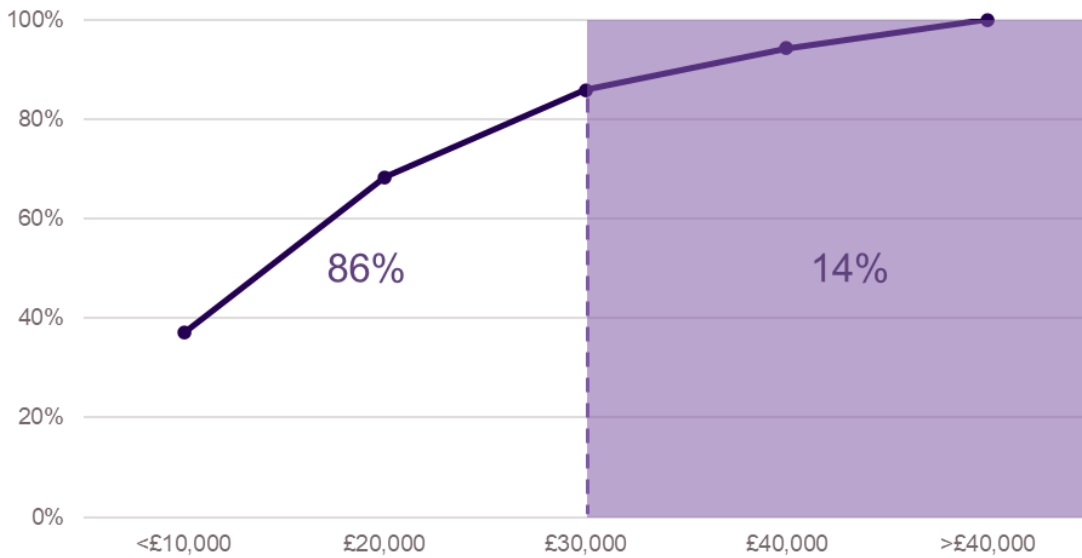




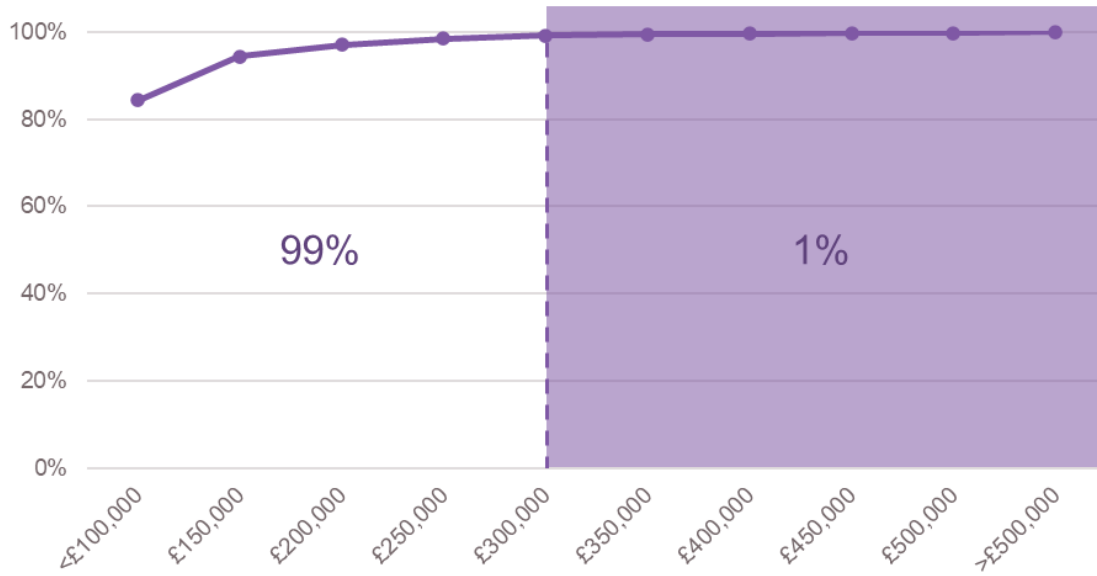
### Life insurance policy values related to the Code's financial limit of £500,000



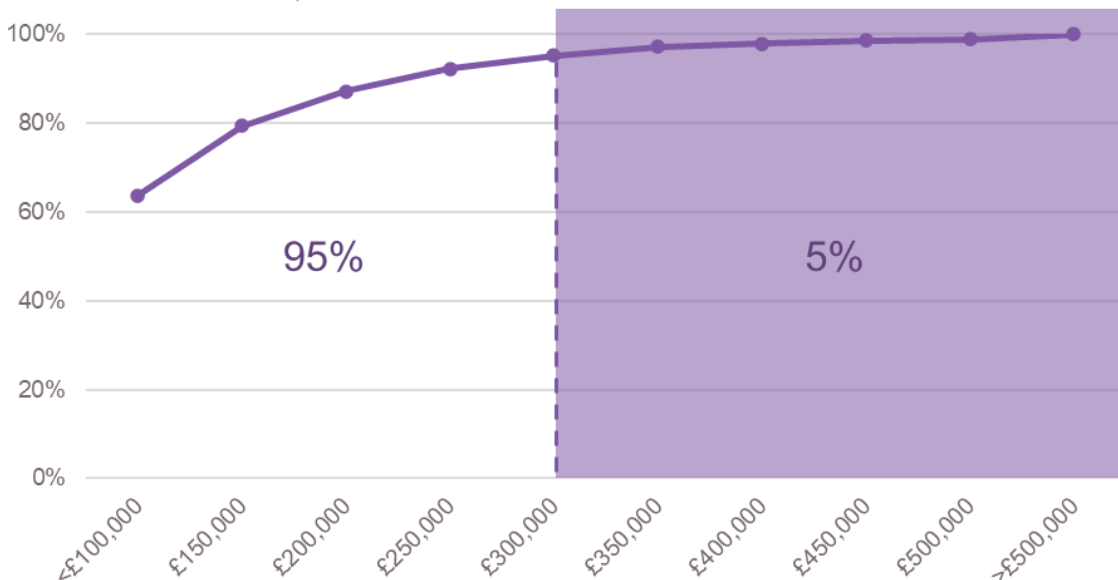
### Income protection insurance policy values related to the Code's financial limit of £30,000 per annum



**Critical illness policy values related to the Code's financial limit of £300,000**



**Accelerated critical illness policy values related to the Code's financial limit of £300,000**



There are two types of critical illness policy shown in the graphs: (1) critical illness and (2) accelerated critical illness. Critical illness policies pay out a lump sum upon diagnosis of a specified illness, whereas accelerated critical illness policies will pay out either on diagnosis of a specified illness or upon death (as a life policy does).

### 3.4 Complaints

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 2023, there were three recorded complaints about the use of a genetic test result by an insurance company. These complaints were resolved between the company and customer.

Commitment 7 of [the Code](#):

*‘Insurers who transact life, critical illness or income protection insurance will:*

- a. Report annually to the ABI their continued compliance with the Code*
- b. Maintain a complaints procedure relating to their compliance with this Code according to the detail set out in the following Q&A’s*
- c. Report annually to the ABI all complaints received relating to the operation of the Code’*

## 4 Conclusion

Continuing developments in genetics and genomic medicine, treatment and research will help to improve the ability to diagnose and treat patients with genetic diseases. Many of the developments are happening within the context of research, and, as such, will not have an impact on the Code.

Commitment 3 of [the Code](#):

*‘Insurers will not ask an applicant to disclose the results of a predictive genetic test:*

- a. taken after insurance cover has started, for the duration of that cover;*
- b. of another person, such as a blood relative; or*
- c. obtained exclusively in the context of scientific research’*

The Government and ABI will continue to publish annual reports. We will review the Code again in 2025 as part of our commitment to three-yearly reviews – to ensure the Code remains relevant and fit for purpose, in light of continuing advances in the field of genomics that are shaping the future of healthcare across the UK.



## 5 Further resources

- The [Code on Genetic Testing and Insurance](#).
- ABI [Consumer Guide: Code on Genetic Testing and Insurance](#) (2023).
- ABI [Genetics FAQs](#).
- Department of Health & Social Care (DHSC) [call for evidence](#) on the Code (2023).
- Department of Health & Social Care (DHSC) [results of call for evidence](#) on the Code (2024).