

2023 Annual Report and Review of the Code on Genetic Testing and Insurance

January 2024



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 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 **£1.5 trillion**, pay over **£17.2 billion** in taxes to the Government and support the UK's communities and businesses.



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1. Background

1.1 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 200 companies, including most household names and specialist providers in the insurance sector.

A productive and inclusive sector, our industry supports towns and cities across Britain in building back a balanced and innovative economy, employing over 350,000 individuals in high-skilled, lifelong careers, two-thirds of whom are outside of London. Our members manage investments of £1.6 trillion, pay over £17.2 billion in taxes to the Government and support communities and businesses across the UK by enabling trade, risk-taking, investment and innovation.

Our industry is also a global success story, the largest sector in Europe and the fourth largest in the world.

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 that have signed up to the Code [on the ABI website](#). 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.

1.2 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. 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.

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

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 and will 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.

1.3 Annual reporting

Under the Code, the ABI and the Government have both agreed to each 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, we will conduct a joint review of the Code every three years to ensure the Code remains fit for purpose. The Government and the ABI agree they must maintain a well-informed shared understanding of the current state of genomic technologies and 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 2022, the insurance industry paid out 98% of life insurance, income protection and critical illness insurance claims, totaling £6.85 billion and equivalent to £18.8 million a day – the highest on record. The average pay out on life insurance policies was £73,578 and it was £21,913 on income protection policies.

2.2 Why genetics is relevant to 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 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 diseases 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, and 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 insurance industry recognises that the public have concerns about the use of genomic information by insurance companies and, more generally, how their data is used. The ABI and its members continue to work with Government, 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 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 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 to provide transparency and confidence in how the Code works.

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 predictive and unknown tests and will ignore these tests when they should not have been disclosed, therefore these will not impact 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 breakdown 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 shows consistent increases in the number of both predictive and diagnostic tests over time and reflects the increasing number of genetic tests taking place in the UK. The increasing trend in diagnostic tests is a more reliable data point than the number of predictive tests as customers should disclose diagnostic tests in insurance applications but in most cases do not have to disclose predictive test results. This means that genetic testing is becoming increasingly prevalent and so of increasing interest and importance to insurers.

Number of Genetic Tests	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
Predictive Results	1410	1571	1878	1700	1458	1336	1407	1754	1937	2123	2118	2255	2401
Diagnostic Results	1474	1718	1980	2035	1879	1753	1827	2061	2779	3476	3502	4076	5169
Other / Do Not Know	134	340	326	314	331	328	360	310	338	388	368	485	508
TOTAL	3246	3629	4184	4049	3668	3417	3594	4125	5054	5987	5988	6816	8078

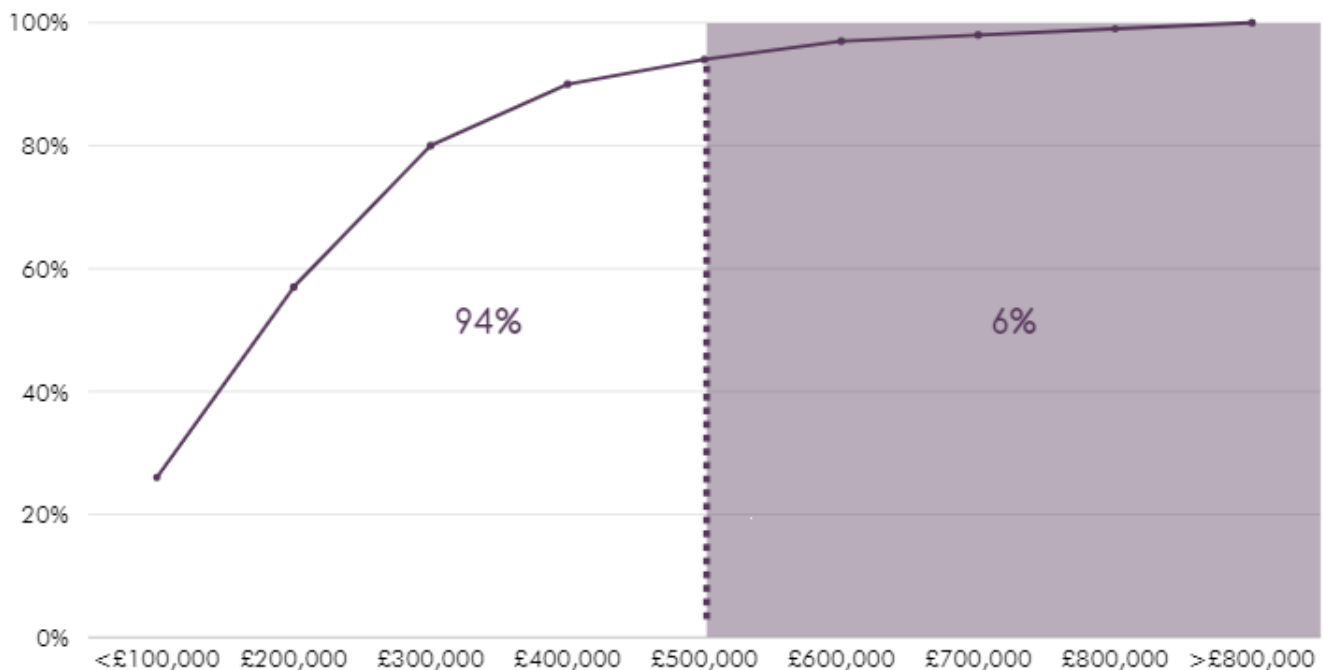
3.3 How the financial limits apply to policies

The graphs below 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, currently only the life insurance limit is 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 2022 94% of life insurance policies fell below the financial limit of £500,000; 93% of income protection policies fall within the limit of £30,000 (per annum); and 99% of critical illness policies and 98% of accelerated critical illness policies fall under the limit of £300,000.

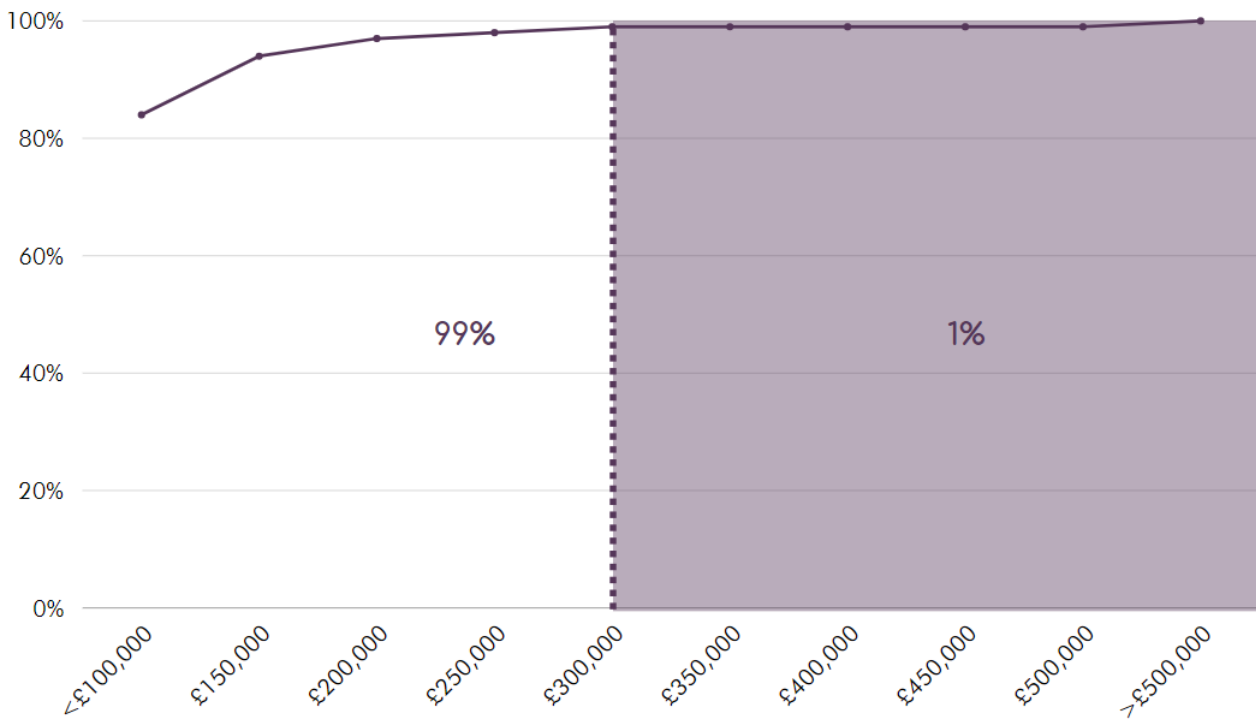
Life insurance policy values related to the Code’s financial limit of £500,000



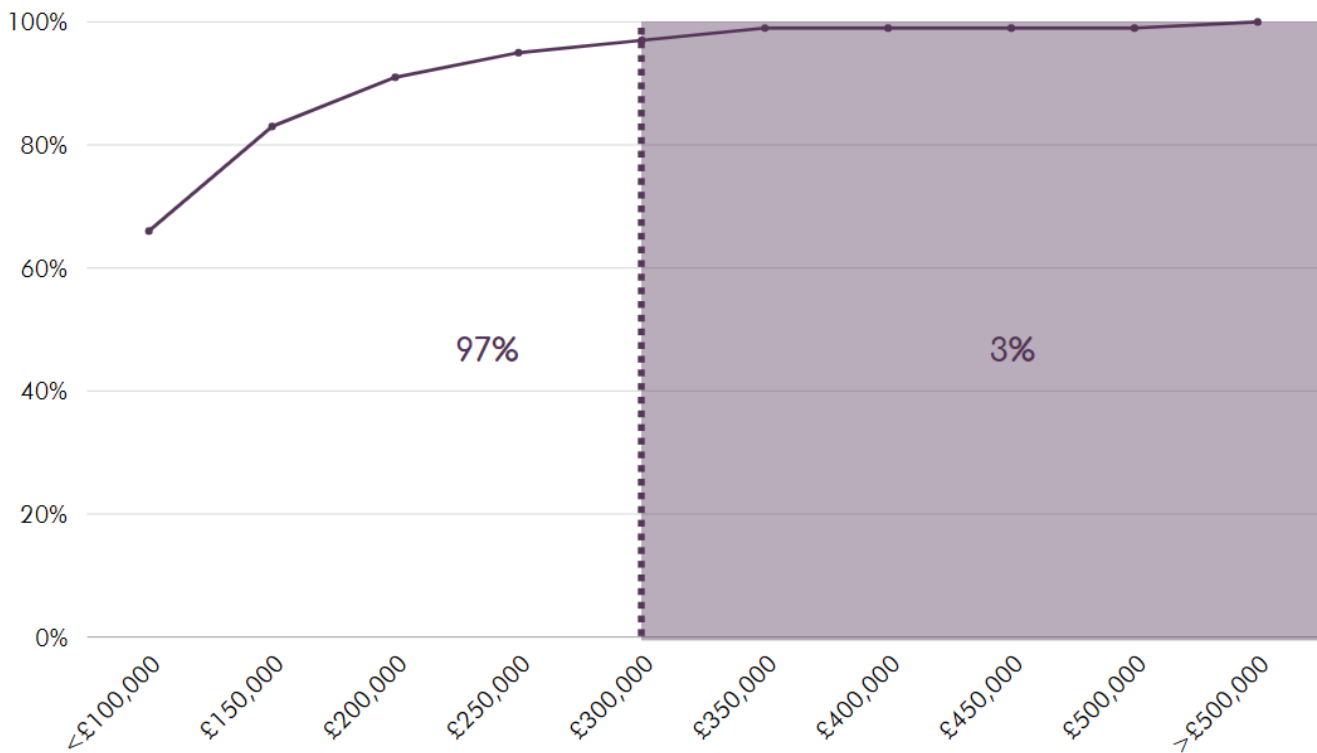
Income protection insurance policy values related to the Code's financial limit of £30,000



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



Accelerated critical illness insurance 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 insurance 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 2022, there was only 1 complaint reported about the use of a genetic test results by an insurance company. It was resolved.