A photograph of a man and a woman in a modern office setting. The woman, on the left, has a large afro hairstyle and is wearing a white blazer over a light blue button-down shirt and blue jeans. She is smiling and looking down at something in her hands. The man, on the right, has a beard and glasses, wearing a grey sweater over a white collared shirt and blue jeans. He is also smiling and looking towards the woman. A purple rectangular box is overlaid on the bottom right of the image, containing the title and date.

# ABI Annual Report: Code on Genetic Testing and Insurance

7 February 2022

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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.*

# 1. Introduction and background

## The Code on Genetic Testing and Insurance

[The Code on Genetic Testing and Insurance](#) (the Code) was published in October 2018, replacing 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. The Government and the ABI also developed a [Q&A to help provide further information](#) about the Code for consumers.

The Code refers to two different kinds of genetic tests:

- **Diagnostic genetic tests** confirm or rule out a diagnosis based on existing symptoms, signs or abnormal non-genetic test results which indicate that the condition in question may be present.
- **Predictive genetic tests** predict a future risk of disease in individuals without symptoms of a genetic disorder.

The Code is the sixth iteration of a long-standing voluntary agreement between Government and the Association of British Insurers (ABI). Insurers signed up to the Code will never require or pressure any applicant to undertake a predictive or diagnostic genetic test, and only consider the result of a predictive genetic test for a very small minority of cases.

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

## Annual reporting

The Code is open-ended with no expiry date. It aims to provide confidence to consumers and represents a commitment from the insurance industry to seek to manage any need for future changes via the agreement.

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. A three-yearly review will allow for the Code to be kept up to date.

A review was scheduled for 2021 but has been delayed to 2022 due to the pandemic reducing the ability to properly review the Code. However, the ABI and Government agreed this delay was feasible due to the absence of any immediate concerns from Government, the ABI or other stakeholders about how the Code is working and which would have necessitated a review in 2021.

To ensure the Code remains fit for purpose, the Government and ABI agree they must have a well-informed, shared understanding of the current state of genomic technologies and the insurance market. To that end the ABI commissioned research with The Cambridge Centre for Health Services Research (CCHSR) RAND Europe and Cambridge University to assess the current impact of genetic testing on the UK insurance market. The key findings are set out in this Annual Report alongside links to the full report.

This is the second Annual Report under the Code from the ABI and provides an overview of the compliance exercise carried out by the ABI to assess how the Code is operating, as well as an overview of the key developments in insurance over the last year. It sits alongside the [Government's Annual Report](#) which includes information on the genomics policy landscape.

## 2. Genetic testing and insurance

### The purpose of insurance

Since its inception, 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 risks.

In 2020, the insurance industry paid out 98% of life insurance, income protection and critical illness insurance claims, totaling £6.2 billion and equivalent to £17 million a day – the highest on record. The average pay out on life insurance policies was £79,304 and £22,000 on income protection policies. In a year of challenge and hardship for people across the UK, a significant proportion of those claims were paid to help the families of those tragically affected by Covid-19.

Insurers are in the business of protecting against the impact of health risks. But they also strongly support changes which improve health and reduce the risk of disease and claims. The evolution of genomic medicine and technologies to improve diagnosis and treatment of patients is a significant development in the UK. Insurers support that development and do not want concerns over access to insurance to inadvertently hinder the uptake in genetic testing to help understand and treat ill health.

As an industry, we recognise that the public have concerns about the use of genomic information by insurance companies and 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.

### Why genetics is relevant to insurance

The Government's Annual Report provides a wider overview of the changes in the genomic policy landscape. Insurers welcomed the Government's 2018 announcement to roll out the world's first whole genome sequencing service for patients with a suspected rare disease and certain cancers. The industry also supports the Government's 10-year strategy – [Genome UK: The Future of Healthcare](#) – to extend the UK's leadership in genomic healthcare and research and its vision to create the most advanced genomic healthcare system in the world to help deliver better health outcomes.

The ABI and its members recognise the development of genetic testing is valuable for informing the diagnosis, prevention and treatment of ill health. This is of huge benefit to the health and happiness of individuals and families. Insurers want to see improvements in health because it is good for society but it is also good for insurance, minimising the risk of ill-health and helping reduce insurance premiums across the population.

The Government also recognises it is important for insurers to access appropriate health information - with relevant consumer consent - so insurers can 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.

Although predictive genetic results may provide an additional source of useful information for insurers, they currently believe the information they already have available to them allows a robust assessment of an individual's risks. That said, the increased use of genetic testing may lead to a cause for concern for the insurance industry if the information individuals have about themselves - but which insurers do not ask for - changes how individuals buy insurance. 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 unsustainable risk management, rising insurance premiums and reduced availability of insurance.

## 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 (providing life, income protection and critical illness) and health insurance (providing private medical insurance). Travel insurers currently have little interest in genetic information – they use health information to underwrite policies but are more interested in the risk of emergency medical treatment when travelling than long term health risk.

Health and protection products are different, but both are concerned about the potential for anti-selection arising from genetic testing. Anti-selection is when there is an asymmetry of information between the customer and insurer – when a customer knows information the insurer does not – and that information increases the customer's likelihood of claiming. If anti-selection becomes widespread insurers could see significantly more claims than they price for.

Protection products are long term and pay out lump sums or regular amounts of money. They are generally only underwritten at the start of the policy but with claims possible at any point from day one to as long as 50 years plus. For those products, trying to assess future risk is critical to helping set the right price for premiums at the start of the policy. 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 risk could lead to more claims than insurers expect and price for, which in turn could lead to an increase in prices for consumers.

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 weren't able to predict and price for. That could lead to insurers excluding certain treatments in new policies if they feel the Code stops them understanding the genetic risks that lead to significant claims. Conversely, the use of genetic information by health insurers could provide an opportunity to help customers reduce health risks shown by predictive genetic tests through the use of preventative treatments.

## CCHSR research


The ABI and its members are committed to working with Government and stakeholders to understand and manage any changes in genetic testing and how these may impact insurance. In 2021, the ABI commissioned The Cambridge Centre for Health Services Research (CCHSR) - a collaboration between RAND Europe and the University of Cambridge - to undertake research to identify the current and potential impact of developments in genetics on the UK insurance industry. Central to this research was the development of a framework for evaluating the potential impacts arising from predictive genetic tests (tests that predict the future risk of developing a health condition, rather than diagnostic genetic tests which are used to confirm whether someone has already developed a condition).

This framework considers the characteristics of genetic tests as well as behavioural aspects that influence the use of genetic tests in the population. It is intended to provide a transparent approach for evaluating whether a specific condition for which a test is available could have an impact on the insurance industry, either currently or in the future, and understanding the key factors that influence this.

The full [independent CCHSR report](#) describes the research and framework with the key findings set out in a short briefing summary.

## Key findings

The research does not currently show evidence of significant anti-selection impacting insurance. However, whilst the research has provided a helpful assessment of the current state of genetic testing, a lack of evidence showing anti-selection does not equate to evidence it does not exist.



Some of the key findings include:

- **The long-term risk to the insurance industry is unclear.** Assessing the risk to the insurance industry presented by genetic tests and associated conditions is determined by a complex interplay of factors. Genetic testing is limited by current knowledge of the genetic variants that increase the risk of developing conditions.
- **Greater use of tests may help reduce health risks.** If genetic testing is used to help target interventions that reduce health risks earlier, this may lead to some conditions presenting less of a risk to insurers over time.
- **NHS testing is largely limited to those with a known family history.** Most of the genetic tests considered by the research only have clinical use in the NHS for people already suspected of being at a higher risk due to a family history or who have shown symptoms. Therefore, access to tests is generally limited to people at a higher risk with use by the general population currently low.
- **Direct-to-consumer genetic tests are not as comprehensive as clinical tests.** Although genetic tests for some conditions can be accessed via direct-to-consumer genetic testing companies, the tests offered are not as comprehensive as those offered by the NHS.
- **Limited evidence that genetic testing influences decisions to buy insurance.** There is limited evidence that genetic test results lead to insurance purchases with existing (and limited) evidence hard to apply to the UK. Equally, insurance purchase decisions do not appear to be a primary motivation for taking a genetic test in the UK, due to access to universal healthcare, relatively low levels of insurance (compared to countries with universal health insurance), and the ABI Code on Genetic Testing and Insurance.
- **Lifestyle change evidence is mixed.** Evidence suggests people at an increased genetic risk for a condition say they are motivated to make lifestyle changes to reduce their risk of ill-health. However, the evidence for behaviour changes actually taking place is more mixed. It also appears to vary depending on the type of health condition and types of lifestyle changes required.

## Outstanding questions

These findings are helpful for showing there are not any immediate concerns about the ongoing effectiveness of the Code on Genetic Testing and Insurance. With an uncertain future, the research prompts further questions and points to areas where research may help identify risks, using the framework created by CCHSR, and set out in their [independent report](#).

These include:

- **Availability of data on genetic tests and conditions.** Making a definitive assessment of the potential risk a genetic condition presents to the insurance industry is complex. It is limited by current data from the UK population on test characteristics, availability and uptake, prognosis and morbidity, and intervention effectiveness and adherence. However, the framework produced by the CCHSR research can act as a guide for determining the areas and types of information that warrant monitoring as research develops further.
- **Comparative lack of UK-based behaviour research.** Research on whether genetic test results have an impact on insurance-related behaviours and lifestyle change is limited and has methodological limitations. Crucially, most research has not been conducted in the UK, making it hard to apply findings from other countries to the UK. Research using UK samples on uptake of and motivations to use genetic tests, and the potential impact of this information on decisions regarding insurance and lifestyle behaviours – such as changes to diet, smoking, and exercise - could help address this gap.
- **Uncertain impact of genetic developments on healthcare and insurance.** The way information about the risk of developing a genetic condition is accessed by individuals and incorporated into the NHS is likely to change over the next 5 to 10 years. But how this might affect the risk presented by people's use of individual genetic tests to the insurance industry is currently unclear.

## 3. Compliance with the Code

### Exceptions within the Code

The financial limits for life insurance, critical illness and income protection products have remained constant without change, and Huntington's Disease remains the only exempt illness (and only for applications for life insurance above £500,000). This means that 100% of applications for life insurance up to the total value of £500,000 are protected from having to share predictive genetic test results.

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

### 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. The majority of 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](#).

### 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 predictive and unknown tests and therefore will not include those results in their risk assessments. Currently, the only times insurers may use predictive tests are when a test result provided voluntarily 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 table shows the continuing increase in both predictive and diagnostic tests, as seen in recent years. This reflects the increasing number of genetic tests taking place in the UK.

We note that the increasing trend in diagnostic tests is a more reliable data point than the number of predictive tests. This is because customers should disclose diagnostic tests in insurance applications but in most cases do not have to disclose predictive test results. Insurers will ignore tests when they should not have been disclosed. It is also important to note the data does not yet breakdown the number of predictive genetic test results to show how many were used to benefit the consumer by mitigating an adverse family history. We hope to be able to show a breakdown in the future.

<b>Number of Genetic tests per year disclosed to insurers</b>	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>	<b>2018</b>	<b>2019</b>
Predictive Results	1700	1458	1336	1407	1754	1937	2123
Diagnostic Results	2035	1879	1753	1827	2061	2779	3476
Other/ Do Not Know	314	331	328	360	310	338	338
<b>TOTAL</b>	<b>4049</b>	<b>3668</b>	<b>3417</b>	<b>3594</b>	<b>4125</b>	<b>5054</b>	<b>5937</b>



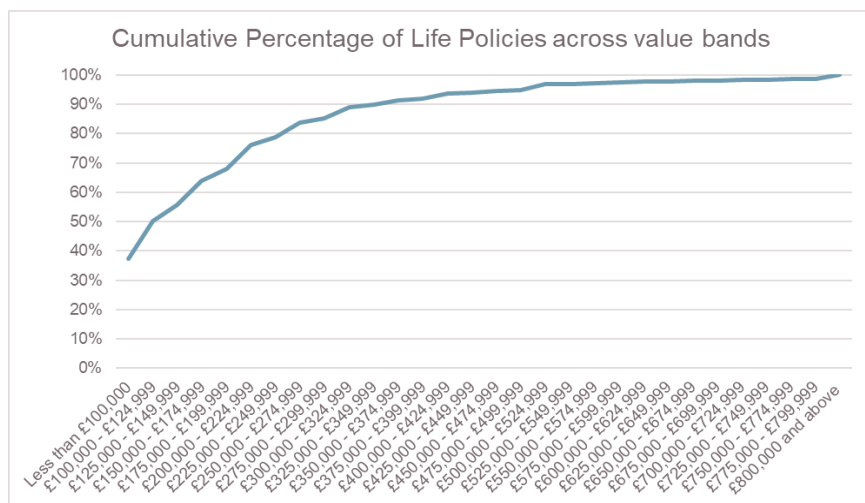
## How the financial limits apply to policies

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 start 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.

With regards to critical illness, there are two types of policy shown in the graphs: critical illness and accelerated critical illness. Both pay out a lump sum at claim but whereas critical illness policies pay out upon diagnosis of a specified illness, accelerated critical illness will pay out either on diagnosis of a specified illness or upon death (as a life insurance policy does) depending on which comes first.

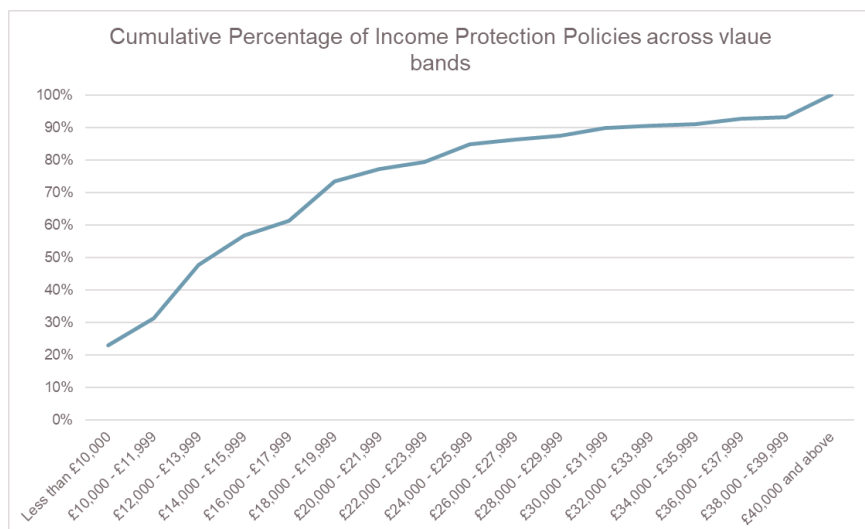
Although it is important to monitor the number of policies underneath these limits, in practice, only the life insurance limit is currently relevant. This is because Huntington's disease for life insurance is the only exception within the Code. The other limits only become relevant should a new exception be applied for and approved.

Currently, 95% of life insurance policies fall within the financial limit of £500,000; 87% of income protection policies fall within the limit of £30,000 (per annum); and, 97% of critical illness policies and 93% of accelerated critical illness policies fall under the limit of £300,000.



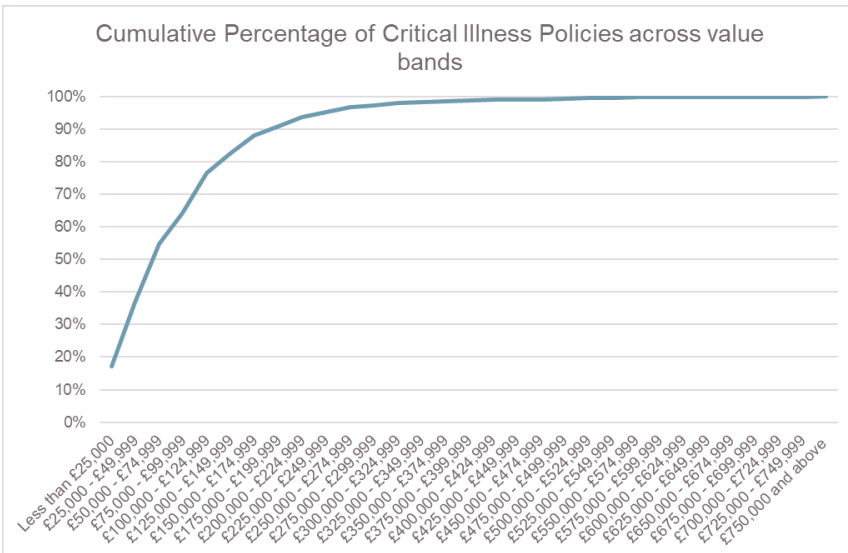
### Life Insurance

95% of life insurance policies fall under the financial limit of £500,000



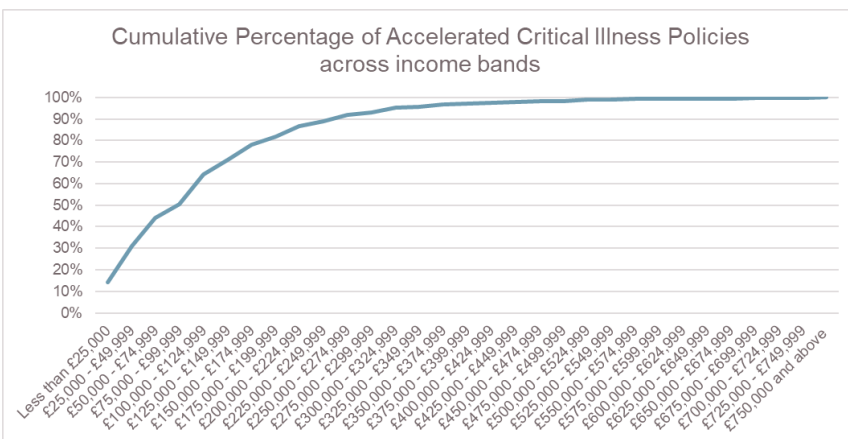
### Income Protection Insurance

87% of income protection policies fall under the limit of £30,000 (per annum)



## Critical Illness Insurance

97% of critical illness policies and 93% of accelerated critical illness policies fall under the limit of £300,000



## 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 2019, there was only one recorded complaint about the use of a genetic test result by an insurance company. This complaint was resolved between the company and customer.



## 4. Conclusion

The Code continues to work well. We do not currently see clear evidence of information asymmetry in the compliance data which might have an adverse effect on the provision of life insurance policies.

The research undertaken by CCHSR has not shown any evidence of a current risk to insurers as a result of the Code. It provides reassurance and a useful framework for identifying risk in the future. It also points to areas for further exploration given uncertainty about the future and the pace of developments in genetic testing.

With only one complaint and no unresolved complaints reported in 2019, the Code on Genetic Testing and Insurance is providing reassurance on how tests are used and not used by insurers. The Code continues to provide reassurance to consumers whilst providing the flexibility to manage change in the wider genetics landscape to ensure that insurers can effectively assess risk and provide insurance to a wide range of people.