



## **Code on Genetic Testing and Insurance**

### **Annual Report 2019**

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#### **Introduction and background**

##### **The Association of British Insurers (ABI)**

The [Association of British Insurers](#) is the voice of the UK's world-leading insurance and long-term savings industry. A productive, inclusive and thriving sector, our industry is helping Britain thrive with 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 industry manages investments of over £1.7 trillion, pays nearly £12bn in taxes to the Government and powers growth 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.

Founded in 1985, the ABI represents over 200 member companies providing peace of mind to households and businesses across the UK, including most household names and specialist providers.

The ABI's role is to:

- Get the right people together to help inform public policy debates, engaging with politicians, policymakers and regulators at home and abroad.

- Be the public voice of the sector, promoting the value of its products and highlighting its importance to the wider economy and society.
- Help encourage consumer understanding of the sector's products and practices; and
- Support a competitive insurance industry, in the UK and overseas.

## **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 life, critical illness and income protection 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 is the sixth iteration of a long-standing voluntary agreement between Government and the Association of British Insurers (ABI), whereby 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 approved relevant predictive genetic test, which is a predictive genetic test for Huntington's disease. However, this only applies to applications for life insurance cover which totals 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.

To ensure that the Code remains fit for purpose, the Government and ABI agree that they must have a well-informed, shared understanding of the current state of genomic technologies and the insurance market. 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 market and developments in genomic medicine, as well as looking at compliance with the Code. A three-yearly review will allow for the Code to be kept up to date.

This is the first 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 provide 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.

## **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 those risks. In 2018, the insurance industry paid out 97.6% of protection insurance claims, totalling more than £5.3 billion, providing financial support to individuals and families going through some of the toughest times such as dealing with bereavement, serious injury or illness.

Given this social purpose, insurers strongly support changes which improve health and reduce the risk of disease. The evolution of genomic medicine and technologies to improve diagnosis and treatment of patients, most notably in cancer and rare disease, is a significant development in the UK. The insurance industry supports developments in genomic medicine and does not want to inadvertently hinder them due to concerns of how genetic tests results could be used by insurers.

The issue that the Code seeks to address is one of trust in the use of genetic information and whether such concerns might deter the use of genomic medicine services to support patient needs. As an industry, we recognise that the public have concerns with the use of genomic information by insurance companies, and how their data is being 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 insurance.

### **Why genetics is relevant to insurance**

The Government's Annual Report provides a wider overview of the changes in the genomic policy landscape. For the industry's part, insurers unequivocally welcome and support the announcement of the Genomic Medicine Service in October 2018, to make the UK the first country in the world to integrate whole genome sequencing into routine clinical care. Insurers want to support the health of their policyholders and so actively support innovations to improve the health of society.

The ABI and its members recognise that genetic testing is a valuable tool in informing the diagnosis, prevention and treatment of ill health. At the same time, insurers do not want people to be discouraged from accessing the benefits of genetic testing because of concerns that the use of genetic information might compromise their ability to access insurance cover.

The Government also recognises that it is important for insurers to access appropriate health information, with relevant consumer consent, so that insurers can effectively assess the level of risk to be covered and offer fairly priced insurance. Asking for relevant information such as details about an individual's family history and socioeconomic data such as health and lifestyle enables insurers to accurately understand the range of risks they are insuring within their risk pool.

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. However, 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. Society is still in the infancy of understanding what genetic information can tell us about future health risk. 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.

## 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.

## Compliance with 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. Some 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 the Concordat and Moratorium which preceded the Code, the ABI reported compliance data to the Health Minister who holds responsibility for genomics policy. This is now being transparently reported by way of this annual report.

The table below sets out the total number of diagnostic, predictive and unknown tests reported to insurance companies in 2018 (with 2019 data to be published later in 2020). Under the terms of the Code, insurers can ask for, and use the diagnostic test results reported to them. The predictive and unknown tests are not requested by insurers and therefore insurers will not incorporate these results in their risk assessments. The only time a predictive test may be used by an insurer, under the terms of the Code, is 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 excepted test over the financial limits.

The data below shows an increase in the number of tests reported in 2018 to those in 2017, in line with the trend of increasing tests in recent years. This reflects the increasing number of genetic tests taking place in the UK. We note that the increasing trend is much clearer for diagnostic than predictive tests. We also note that the increasing trend in diagnostic tests is a more reliable measure as diagnostic tests are disclosed as a matter of course during underwriting, whereas insurance applicants can decide whether or not to disclose predictive test results. It follows that trends in predictive tests may be distorted by changes in disclosure rather than changes in the number of actual relevant tests. It is also important to note that the data does not breakdown the number of predictive genetic test results to show how many were inadvertently disclosed and so ignored and how many were used to benefit the consumer by mitigating an adverse family history. We will aim to improve this data in future annual reports.

Number of Genetic tests per year disclosed to insurers	2012	2013	2014	2015	2016	2017	2018
Predictive Results	1878	1700	1458	1336	1407	1754	1937
Diagnostic Results	1980	2035	1879	1753	1827	2061	2779
Other/ Do Not Know	326	314	331	328	360	310	338
<b>TOTAL</b>	<b>4184</b>	<b>4049</b>	<b>3668</b>	<b>3417</b>	<b>3594</b>	<b>4125</b>	<b>5054</b>

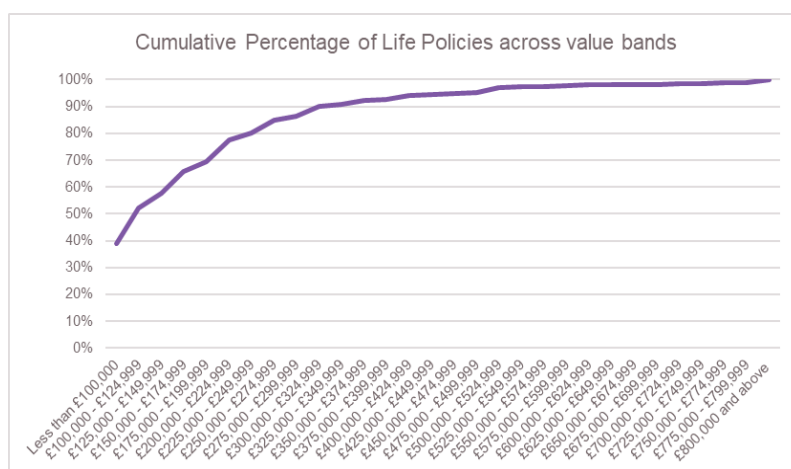
## How the financial limits apply to policies

The graphs below show the distribution of life, income protection and critical illness insurance policies written in 2018 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 of how many policies apply to the limits each year 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 which comes first.

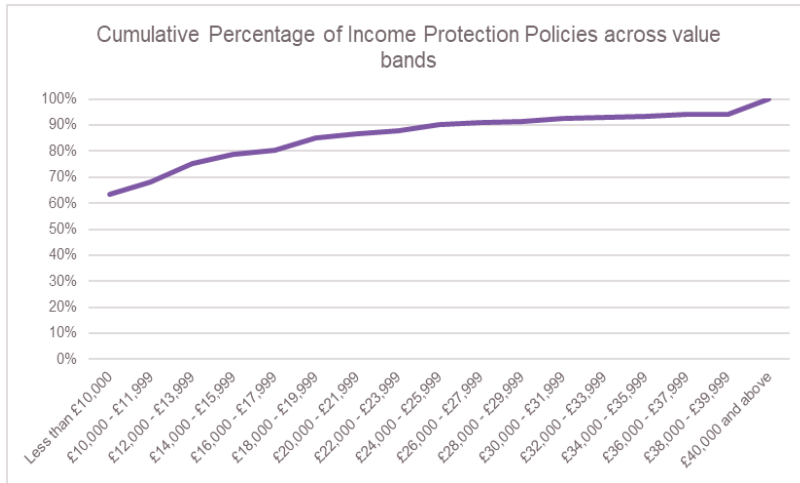
Although it is important to monitor the number of policies underneath these limits, in practice, only the life insurance limit is currently in effect. This is because Huntington's disease for life insurance is the only exception within the Code. The other limits are there should a new exception be applied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

As is stands: 95% of life insurance policies fall within the financial limit of £500,000; 91% of income protection policies fall within the limit of £30,000 (per annum); and, 98% of critical illness policies and 94% of accelerated critical illness policies fall under the limit of £300,000.



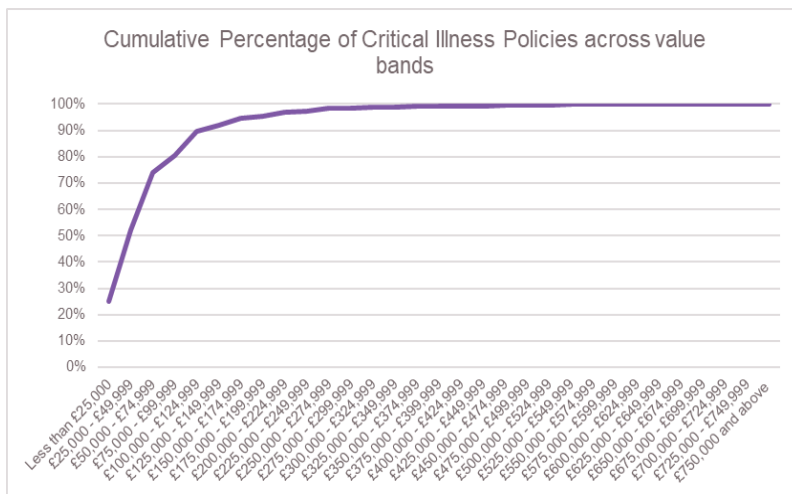
### Life Insurance

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



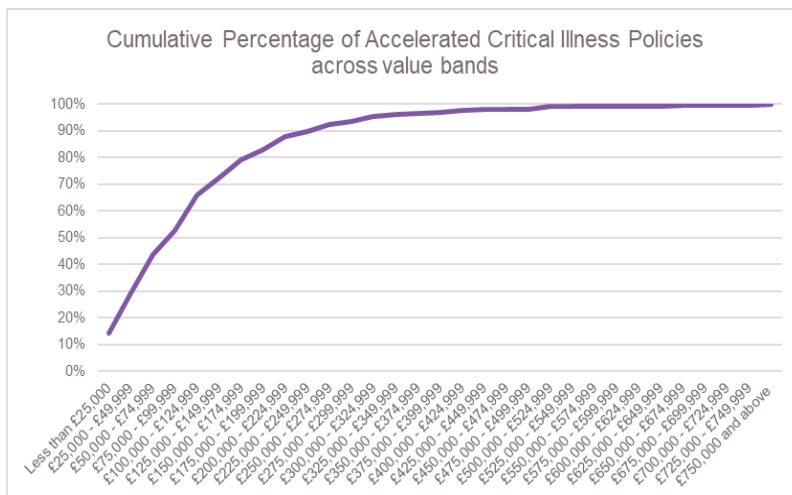
### Income Protection Insurance

91% of income protection policies fall under the limit of £30,000 (per annum)



### Critical Illness Insurance

98% of critical illness policies and 94% 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 2018, there were no complaints reported about the use of a genetic test results by an insurance company.

## Conclusion

In our view the Code is currently working well. We see no indication in the compliance data of a current information asymmetry that might have an adverse effect on the provision of life insurance policies. However, we will continue to review the data annually, as well as monitoring advances in genetic testing.

With no complaints reported in 2018, the Code on Genetic Testing and Insurance is providing clarity on how tests are used and not used by insurers. The Code, as with its prior version, continues to provide a framework for providing reassurance to consumers whilst providing the flexibility to manage change in the wider genetics landscape to ensure that insurers can effectively assess the level of risk to be covered and provide insurance to a wide range of consumers.

This annual report is a step towards improving both transparency of the data used by insurers, and the understanding of what information insurers use to assess risk to balance the interests of the public and insurers. It also helps to facilitate an ongoing dialogue between insurers, Government and consumers.