



HM Government



# Code on Genetic Testing and Insurance

A voluntary code of practice agreed between HM Government and the Association of British Insurers on the role of genetic testing in insurance

October 2018

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### 3 Code on Genetic Testing and Insurance

# Introduction

**This Code has been developed between the Government and the Association of British Insurers (ABI) on behalf of its members and describes a shared agreement on the role of genetic testing in insurance. It builds on and replaces the previous Concordat and Moratorium on Genetics and Insurance.**

This Code and the Commitments concern what use insurers can make of genetic test results of individuals who are applying for insurance and 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.

Both the Government and the ABI recognise that genetic testing is a valuable tool in informing the diagnosis, prevention and treatment of ill health and people should be not be discouraged from accessing its benefits because of concerns this might compromise their ability to access insurance cover. The Government and ABI also recognise that it is important for insurers to access proportionate levels of relevant health information, given the appropriate consent, so that they can offer fairly

priced insurance. As a result, both parties have worked together to develop a Code which strikes a fair balance between both interests and sets out clear standards for insurers and customers regarding genetic testing and insurance.

To achieve this balance, the Code is based on two core principles:

- An insurer will not require or pressure an applicant to undertake a predictive or diagnostic genetic test in order to obtain insurance.
- The results of a predictive genetic test may be considered in an application for insurance only when both of the following conditions are met:
  1. This Code states that the specific predictive genetic test may be considered and;
  2. The sum assured exceeds the financial limits set out in this Code.

Building on these two principles, the ABI has developed a set of Commitments made by all relevant ABI members on the use of **predictive genetic test results** in insurance applications, which the Government has endorsed. The Commitments set out the types of insurance to which predictive genetic test results may be relevant, the financial limits that define the very largest policies, and when and how predictive genetic test results will be processed in a

Type of insurance	Financial limits above which predictive genetic tests may become relevant	Medical conditions for which insurers may ask for and take account of predictive test results, for policies above the financial limits
Life Insurance	£500,000 (per person)	Huntington's disease
Critical Illness Insurance	£300,000 (per person)	None
Income Protection Insurance	£30,000 per annum (per person)	None
All other types of insurance	Predictive genetic test results will not be asked for, or taken into account, whatever the level of cover.	

manner that is transparent to the applicant. Non-ABI member insurers are encouraged to sign-up to the Code and the Commitments.

Under this Code, ABI member insurers who provide one-off or annual policies such as travel 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 sets out how genetic information is treated by insurers who provide life, critical illness and income protection insurance.

The Government and the ABI recognise that certain types of health information, such as an applicant's medical report, can be relevant when pricing risk. Many types of genetic tests can be carried out to confirm diagnoses of ill-health. In the same way as the diagnostic results of a blood test or MRI scan, a diagnostic genetic test result may therefore form part of relevant medical information when making an application for insurance. The Code recognises this and, as a result, only concerns genetic test results that are predictive of future ill health, known as predictive genetic tests.

A summary of how the Code translates into practice is shown in the table above.

Dame Sally Davies, England's Chief Medical Officer (CMO), gave detailed consideration to the relationship between genomic information and insurance in her 2016 independent report on genomics, entitled '[Generation Genome](https://www.gov.uk/government/publications/chief-medical-officer-annual-report-2016-generation-genome)'<sup>1</sup>. She concluded with her support for the 'long-standing Government policy of maintaining a flexible semi-voluntary regulatory structure for this area' and made several recommendations which have guided the review of the previous Concordat and Moratorium on Genetics and Insurance, leading to this Code.

Informed by the CMO's observations, this Code retains the key principles of the previous Concordat and Moratorium and reflects relevant legislation and recommendations that have been made since the agreement was last reviewed. Unlike the previous Concordat and Moratorium, the Government and the ABI have agreed to make this Code open-ended, to provide longer term certainty to customers. The Government and the ABI will seek to address where possible changes in the genetic testing environment and any impact on the insurance market via changes to the Code, rather than withdrawing the Code.

<sup>1</sup> <https://www.gov.uk/government/publications/chief-medical-officer-annual-report-2016-generation-genome>

The Government and the ABI will publish an annual report, which will 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 then allow for the Code to be kept up-to-date.

Finally, it is important to recognise that this Code does not stand alone. It is designed to supplement existing legislation on the use of medical information for insurance purposes, as set out in the Data Protection Act 2018, Access to Medical Reports Act 1988, the Consumer Insurance (Disclosures and Representations) Act 2012, the Equalities Act 2010 and Insurance Act 2015, as well as good industry practice. The Code is also consistent with the Council of Europe's Recommendation on the processing of personal health-related data for insurance purposes, which sets out principles by which member States can ensure respect for the fundamental rights of individuals, without discrimination, in the context of insurance contracts. The Government will continue to promote clear advice and guidance for professionals seeking consent for clinical or research purposes and for dealing with requests for medical information where they are relevant for insurance purposes. Individuals applying for insurance must also take reasonable care not to misrepresent information to an insurer when buying insurance cover.

The remainder of this Code sets out the Commitments made by the ABI, on behalf of its members, and sets out the processes involved in reviewing the Code and in making any changes to the list of relevant predictive genetic tests for policies over the financial limits in future. In all aspects of the Code, the ABI and its members will 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.

# The Commitments

Made by the Association of British Insurers  
on behalf of its members

1. 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 below.
2. 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.

3. 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

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.
7. 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
8. 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. The number of NGUs should be proportionate to the scale of the business.



# Questions and answers regarding this Code

The ABI, its members and the Government agree that the Code and its Commitments

## When does the Code apply?

This Code replaces the “Concordat and Moratorium on Genetics and Insurance” from [October 2018]. It aims to replicate the content of the Concordat and Moratorium in a way that is easier to understand for consumers, so that the benefits and protections offered by the previous Concordat and Moratorium are communicated more clearly.

The Code is open-ended and will be reviewed every three years to allow it to remain up-to-date. Details about how reviews will be undertaken are given on page 11.

## To which insurers does this Code apply?

Compliance with the Code and the adoption of the Commitments in the Code is a condition of membership for all ABI members. A full list of ABI members can be found [here](#)<sup>2</sup>.

While the ABI is unable to offer Commitments on behalf of any insurer who is not a member, the ABI invites any insurer who provides life, critical illness or income protection insurance in the UK to comply with the Code if they recognise and agree with the principles on which it is based. Such insurers should notify the ABI in writing if they will comply with the Code and would subsequently be included in the ABI’s published list of compliant insurers.

represent good industry practice and are consistent with all relevant legislation including the Data Protection Act 2018, the Equalities Act 2010, the Access to Medical Reports Act 1988, the Consumer Insurance (Disclosure and Representations) Act 2012 and Insurance Act 2015. The Code is therefore likely to be referenced by relevant regulators such as the Financial Ombudsman Service and Information Commissioner’s Office (ICO) when considering the actions of those insurers who are not ABI members and who do not sign up to the Code.

This Code is a voluntary agreement between the ABI and Government and its content is not legally binding.

## To what types of insurance does the Code apply?

The Code applies to life, critical illness and income protection policies according to the following descriptions:

- **Life insurance.** Any policy where the main benefit is a payment to a designated beneficiary on the death of the person insured. Most of these policies will be called life insurance but variations include Term Assurance, Whole Of Life and Life Assurance.

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<sup>2</sup> <https://www.abi.org.uk/about-the-abi/abi-members/>

- **Critical illness insurance.** Any policy where the main benefit is a payment to someone covered by the policy if they are diagnosed with a specific condition which is covered by the policy. Most of these products will be called Critical Illness Insurance but some insurance companies may give them a different name, such as Serious Illness Benefit.
- **Income protection insurance.** Any policy which pays a sum or sums of money, usually a percentage of salary, to give financial support if the person insured cannot work due to illness or injury. Other names for this might include Personal Sick Pay or Disability Insurance.

The Code applies to all ABI members. ABI member insurers providing one-off or annual policies, such as travel insurance, motor insurance and private medical insurance, will not ask for or use the result of a predictive genetic test, in any circumstance, to set insurance premiums. Predictive genetic information is of most relevance for ABI members providing life insurance, critical illness insurance or income protection insurance, as these are long-term insurance products which require medical underwriting. It is for this reason that this Code and the Commitments set out how results of genetic tests are treated in relation to life insurance, critical illness insurance or income protection insurance.

If you are unsure whether an insurance policy you are considering taking out is subject to the Code you should contact the ABI via their website.

### **When and what type of medical information, including genetic test results, should be disclosed to insurers who comply with this Code?**

The Government and the ABI agree that insurers are lawfully permitted to seek access to appropriate family medical history and to reports from general practitioners where relevant to applications for health-related policies, such as life, critical illness and income protection insurance provided they comply with data protection requirements. When insurers wish to obtain medical information they will first ask for consent from the applicant.

Under this Code, a genetic test refers to a test which 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.

In the same way as a blood test or MRI scan, genetic testing can be used to confirm diagnoses of ill health. The results of diagnostic genetic tests can therefore form part of relevant medical information in such applications. In these instances, insurers will be able to access the results of a diagnostic genetic test 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 held by a general practitioner as set out in the Access to Medical Reports Act 1988 and by [ABI guidance](#)<sup>3</sup>, created in consultation with the ICO and the British Medical Association.

Individuals applying for insurance must also take reasonable care not to misrepresent information to an insurer when buying insurance cover. Rules regarding the disclosure of medical information in applications for insurance are set out in detail in the Consumer Insurance (Disclosures and Representations) Act 2012 and are summarised in the ABI's guidance [‘What the Consumer Insurance Act](#)

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<sup>3</sup><https://www.abi.org.uk/globalassets/sitecore/files/documents/publications/public/2017/health/requesting-and-obtaining-medical-information-electronically.pdf>

[means for customers](#)<sup>4</sup>.

This Code and the Commitments therefore concern what does and does not need to be disclosed to an insurer when it comes to the results of a **predictive genetic test result**, and how such a result will be taken into account if it is disclosed. It is also important to note that insurers agree to not require or pressure an applicant to undertake **any** type of genetic test, whether diagnostic or predictive, as a condition of obtaining insurance. If applicants remain unsure about what they do and do not need to disclose, they can find further [guidance](#)<sup>5</sup> on the Genetic Alliance UK website.

This Code covers the disclosure of predictive genetic tests regardless of the purpose for which they were obtained. This includes, but is not limited to, a voluntarily purchased, direct-to-consumer test, one taken on the recommendation of a clinician or one taken as part of any scientific research.

As per Commitment 3c, a 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. If, as a result of genetic testing through scientific research, a relative who is not part of the research project is referred for genetic testing (called cascade testing), that relative's genetic test result would not fall under the exemption of scientific research and they may need to disclose the result, according to Commitment 2, if they apply for insurance.

The Code does not apply to other non-genetic medical tests such as urine, blood or cholesterol tests, MRI or CT scans or ECGs.

### **What happens if a predictive genetic test result is voluntarily disclosed?**

Where a test is disclosed voluntarily, insurers will act according to Commitment 6.

As per Commitment 5, insurers will also make clear before an application for insurance is completed how an insurance decision may be affected if an applicant decides voluntarily to disclose a favourable predictive genetic test result. Applicants are therefore encouraged to take this into account when shopping around for an insurer.

### **What happens if a customer has a complaint relating to an insurer's compliance with the Code?**

Customers (including those applying for insurance) are entitled to ask an insurer to provide information on whether and, if so, how a predictive test result has contributed to the decision made by the insurer regarding their application for insurance. This could include the decision to offer cover with a standard or increased premium, cover with certain exclusions or no cover at all. Insurers that receive a request for this information will provide a written response to the applicant within 10 working days.

Based on this information, if a customer has reason to believe that the insurer has not acted according to this Code, they can make a complaint to the insurer. Insurers will consider that complaint fairly and – if they transact life, critical illness or income protection insurance - by reference to their leading Nominated Genetic Underwriter (NGU) and will respond to the customer explaining the firm's final decision and the reasons for it within a further 10 working days. This communication will also inform the customer about any further action they can take, with relevant details, if they remain unsatisfied.

Depending on the circumstances of the case, the further action open to customers may include the following:

- The customer may have a complaint about the insurer's compliance with the Code and

<sup>4</sup> <https://www.abi.org.uk/data-and-resources/tools-and-resources/how-to-buy-insurance/what-the-consumer-insurance-act-means-for-customers/>

<sup>5</sup> <http://www.geneticalliance.org.uk/information/living-with-a-genetic-condition/insurance-and-genetic-conditions/>

its Commitments. Customers can complain directly to their insurer, all of whom set out how they handle complaints as required by the Financial Conduct Authority (FCA); or

- In cases where the complaint concerns a contract that has been concluded, the customer has the right to have the complaint considered by the (free to customers) Financial Ombudsman Service if the customer believes they have suffered, or may suffer, a financial loss, material distress or material inconvenience as a result of the insurer's wrongful act or omission; or
- The customer may take legal action against the insurer.

This process aims to align with FCA Handbook on how complaints are to be dealt with by insurers. Should there ever be any contradiction between the two, the FCA Handbook process should always be followed over the process set out in this Code.

### **How will compliance with the Code be monitored?**

Compliance with the Code is a condition of ABI membership; insurers not within ABI membership can publicly state their intention to comply with the Code and to report relevant compliance data to the ABI. The ABI website will set out which insurers are complying with the Code.

On an annual basis, each insurer who has signed up to the Code will confirm to the ABI via their Chief Underwriter or Head of Compliance that they continue to comply with the Code. They will also report to the ABI the number of complaints received regarding their compliance with the Code, as detailed in the previous section.

This information will be used to inform the content of an annual report from the Government and the ABI, which will be made publicly available. The annual report will include the number of complaints, if any, and the total number of relevant policies sold in the previous year. The compliance of relevant

insurers will be considered when the Code is reviewed on a three-yearly basis.

### **What is an annual report?**

To ensure that the Code remains fit for purpose, the Government and the ABI agree that they must have a well-informed, shared understanding of the current state of genomic technologies and the insurance market. The Government and the ABI also acknowledge that what can cause concern for customers and insurers alike is uncertainty, or unexpected change.

This is why both parties have agreed to publish an annual report concerning the Code. Each report is intended to provide an update on the state of the insurance market and developments in predictive genetic testing, as well as looking at compliance with the Code. In particular, the reports can be used to monitor how the financial limits relate to the bulk of insurance policies over time and can look at changes in the prevalence and predictiveness of genetic testing, as well as sharing improved knowledge on the treatment and management of relevant genetic diseases.

In line with the Council of Europe Recommendation on the processing of personal health-related data for insurance purposes, the reports will aim to promote collective consultation between the Government and the ABI, as well as public transparency.

### **How will the Code be kept up-to-date?**

The ABI and the Government have worked together to develop this Code in a way that balances the interests of consumers in obtaining affordable insurance, and insurers' interests in obtaining relevant information to assess risk, whilst reflecting the current capability and prevalence of genetic testing.

The Government and the ABI have agreed to provide longer term certainty by making this Code open-ended. Both parties recognise that for an open-ended agreement to remain effective and relevant, it needs to be kept up-to-

date. This is so that it can align with the most recent legislation and guidelines, as well as reflecting the evolving state of genomic medicine and the insurance market. It is for this reason that the Government and the ABI agree that the Code should be reviewed, in a joint process, every three years.

The review process will consider relevant annual reports and may be taken as an opportunity to clarify the workings of the Code, such as the procedures for complaints and monitoring. Evidence would also be considered to assess whether the financial limits provided for in Commitment 2 continue to offer reassurance by covering the vast majority of policies, leaving only the largest policies above the limits.

Such review processes may seek to clarify and improve the current Code, including any updates that are necessary to reflect developments in genomic medicine and the insurance market. However, two principles are fundamental to the Code and would not be changed at such reviews unless there was a fundamental rethink of this Code:

- An insurer will not require or pressure an applicant to undertake a predictive or diagnostic genetic test in order to obtain insurance.
- The results of predictive genetic tests may only be considered in an application for the very largest relevant insurance policies and only for conditions which have been shown to be highly predictive of a relevant risk.

Both the Government and the ABI will publicise on their respective websites the date of the next review. Reviews would take account of any relevant evidence from patient groups and other appropriate stakeholders.

Any changes that may be made to the Code through the process of a review will take effect immediately upon publication, unless specified as part of the review.

Both Government and the ABI acknowledge that the environment could change such that it is

no longer possible for the Code to be mutually supported. Several possible scenarios could necessitate a wider public debate on the role of predictive genetic tests in insurance. For example: a policy decision could mean that the Government can no longer endorse the Commitments in the Code; the ABI, on behalf of its members, could conclude that significant levels of anti-selection (individuals buying insurance based on information that insurers do not know) could undermine their ability to offer affordable insurance to customers; or there may be lack of consensus in relation to an Application for the addition of a new condition to Appendix I. In these circumstances, the Government and ABI would work together in order to communicate clearly any implications.

### **What is the process for changing the list of relevant predictive genetic tests in Appendix I?**

The ABI will give Government as much notice as possible of its intention to make an application to change the list of predictive genetic tests in Appendix I (an “Application”).

An Application will be submitted in writing by the ABI to Government and will be published by the ABI on its website within one month of the written submission.

The Application will identify the condition which the ABI on behalf of its members submits as appropriate for inclusion in Appendix I, and will include evidence and any relevant research to demonstrate that:

- The condition identified is inherited in a clear and measurable manner and which has a high probability that those with the particular gene variant will develop the condition, leading to a materially increased likelihood of significant morbidity and/or mortality.

- That a predictive genetic test is available<sup>6</sup> which is of a high:
  - ❖ **analytical validity** (how well the test predicts the presence or absence of a particular gene or genetic change)
  - ❖ **clinical validity** (how well the genetic variant being analysed is related to the presence, absence, or risk of a specific disease)
  - ❖ **clinical utility** (whether the test can provide information about diagnosis, treatment, management, or prevention of a disease that will be helpful in a clinical context)
- There is a material risk of anti-selection (individuals buying insurance based on information that insurers do not know) which would have a material impact on individual premiums, and so a detrimental cost to consumers and insurers, if not addressed.
- A revised version of the Code will be published by the ABI and Government as soon as possible;
- The change shall take effect not more than 3 months after the Government communicates its decision to the ABI; and
- The Government will give due regard to the need for any supporting materials and guidance.

Following publication of the Application:

- The ABI will engage with Government and relevant external stakeholders to obtain input and views on the Application within 3 months of publication.
- The ABI will initiate an independent peer review to consider the Application, report upon the Application and make a non-binding recommendation within 6 months of publication. The peer review will be conducted by not less than four appropriate independent experts such as a patient representative, clinical geneticist, epidemiologist, economist or actuary.
- The Government will give its decision in writing to the ABI within 6-12 months of publication of the Application.

If, as a result of an Application, any change is made to the list of relevant predictive genetic tests in Appendix I:

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<sup>6</sup> for example as indicated in England through inclusion in NICE clinical guidelines and / or the National Genomic Testing Directory



# Appendix I

## Accepted Conditions

Below is a list of the only condition(s) for which insurers may request disclosure of predictive genetic test results in accordance with the financial limits set out in Commitment 2:

- Huntington's disease, for life insurance coverage totalling above £500,000 per individual

## Appendix II

# ABI duties and responsibilities of a Nominated Genetics Underwriter

### Insurance Industry Commitments on Predictive Genetic Tests – Guidance for Insurers NGU Checklist - Duties and responsibilities of the Nominated Genetics Underwriter

The purpose of this checklist is to help ABI members comply with the Commitments. When in doubt, please refer to the actual wording of the Commitments as outlined on pages 6&7 of this Code.

#### Nominated Genetics Underwriters

- All ABI member firms who carry out direct business and medically underwrite life, critical illness, or income protection insurance must appoint a senior underwriter to act as the firm's Nominated Genetics Underwriter (NGU). The NGU will be the central reference point within the company for each application in which a genetic test result is disclosed.
- Where relevant to their work, reinsurers should also have an NGU and abide by the practices below.
- The firm must also appoint one or more deputy NGUs to cover the absence of the NGU. This does not have to be a member of staff, but the firm remains responsible for compliance.
- The NGU must be registered with the ABI as the company's NGU – all new NGUs should register by confirming details to the ABI ([ABIStatistics.Service@abi.org.uk](mailto:ABIStatistics.Service@abi.org.uk)).

#### NGUs have the following responsibilities:

- To hold, and to have a thorough knowledge of, an up-to-date copy of the Commitments.
- To keep up-to-date with relevant developments in genetic science and technology including with evidence as it relates to the conditions in Appendix I.
- To assist with, and where appropriate provide, education and training for relevant staff.
- To maintain a log of all applications where a genetic test result is disclosed. The log must contain:
  - Genetic test / condition.
  - Genetic test result (adverse/positive, favourable/negative/normal).
  - Genetic test type (predictive, diagnostic, carrier).
  - Was the genetic test carried out in context of a clinical trial.
  - Year the genetic test was taken. Date of application.



- Product, and rider, applied for.
- Genetic test result route of disclosure (customer, GP, medical adviser). Applicant's date of birth.
- Underwriting decision.
- Reason for underwriting decision (medical history, family history, non-medical information).

- To consult a medical practitioner, normally the firm's Chief Medical Officer, on any application involving genetic medical evidence that is unfamiliar and/or complicated.

- To disregard any test where it is not clear whether or not it is covered by the Commitments.

- To ensure that genetic information disclosed when an insured person makes a claim, and that was not disclosed at application stage, is treated in accordance with the Commitments. For instance:
  - If the person does not have to disclose at application because of the Commitments, but makes a claim after the Commitments ends, the Commitments rules at the time of the application will apply at the time of the claim.
  - Predictive genetic tests results not disclosed until the point of claim will not impact on payment of the claim unless the insured person was asked to disclose the information in line with the terms of the Commitments applicable at the time of application (that is, the application was for insurance over the Commitments' financial limits and it was a test approved for use).

- To assist with and contribute to the development of the firm's internal systems and processes to ensure that these take account of the requirements of the Commitments.

- To maintain a log of complaints about a breach of the Commitments.

- To report any breach of the Commitments to the person responsible for compliance, and to assist in implementing any corrective action.

- To comply with the ABI's compliance reporting requests, specifically:
  - NGUs to submit annual information on genetic test results and complaints – each year NGUs will report 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 (including complaints not yet resolved) during the period 1 January – 31 December.
  - Complaints reported to ABI as resolved/closed - firms will report to the ABI on individual complaints about a breach of the Commitments. Individual complaints should be reported to the ABI once resolved/closed.

- To support their firm's compliance confirmation process.

## Appendix III

# Relevant provisions and useful publications

### Relevant provisions and industry guidance

Nothing in these Commitments should be regarded as conflicting with insurers' statutory and regulatory requirements or other professional duties and obligations. Several statutory and regulatory requirements along with other industry guidance are relevant to insurers in their use of genetic and health information. Some of these are listed below:

- **Equality Act 2010** - The Equality Act 2010 legally protects people from discrimination in the workplace and wider society. Guidance on the Act can be found [here](#)<sup>7</sup>.
- **Data Protection Act 2018** - The new Data Protection Act came into effect in the UK in May 2018. Experience with the Concordat and the Council of Europe recommendation suggests that general legislation on data protection, equalities and financial services provides a strong basis for self-regulation to underpin this type of agreement between Government and industry. This act sets out responsibilities of insurers and general practitioners as Data Controllers.
- **Access to Medical Reports Act 1988 (AMRA)** – This Act determines how insurers, and other third parties, should request medical information from GPs and must include the explicit consent of the individual. In Northern Ireland, this request is made under the Access to Personal Files and Medical Reports (Northern Ireland) Order 1991.
- **Council of Europe Recommendation concerning genetics and insurance** - On 26 October 2016 the Council of Europe adopted Recommendation CM/Rec (2016) 8, which covers the use of predictive health information for insurance purposes and introduces high level principles based on the Council of Europe's Conventions on data processing and on human rights and biomedicine.
- **ABI principles for requesting and obtaining medical information electronically from GPs** - The ABI has published Principles for requesting and obtaining medical information electronically from GPs. These Principles were put together by the ABI with members and with input from the British Medical Association and the Information Commissioner's Office, and can be found [here](#)<sup>8</sup>.

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<sup>7</sup> <https://www.gov.uk/guidance/equality-act-2010-guidance>

<sup>8</sup> <https://www.abi.org.uk/globalassets/sitecore/files/documents/publications/public/2017/health/requesting-and-obtaining-medical-information-electronically.pdf>

## Useful publications

Those wishing to learn more about the role of genetic tests and insurance might be interested in the following publications:

- **Code on Genetic Testing and Insurance: Consumer FAQs** – This FAQ document includes general information for consumers about the use of medical records in insurance, as well as specific information about the role of genetic testing and insurance, including genetic tests obtained through research. You can find the FAQs [here](#)<sup>9</sup>.
- **Code on Genetic Testing and Insurance: Consumer Guide** – This guide provides a short and easy to read summary of the Code for consumers. You can find the consumer guide on the Code [here](#)<sup>10</sup>.
- **Genetic Tests and Insurance: What you need to know** - This consumer guide is for people who are thinking about taking a genetic test and want to know how this could affect their insurance. You can find the consumer guide [here](#)<sup>11</sup>.
- **Insurance and genetic conditions** - Genetic Alliance UK have a [page](#)<sup>12</sup> on their website which gives further information regarding insurance and genetic conditions.
- **GP report insurance package** - The BMA has worked with the ABI to compile a pack including: a standard covering letter for insurers to send to GPs, together with an overview of the types of information that are relevant to different types of insurance policy; a standard GPR form; and a standard consent declaration for patients. The pack can be found [here](#)<sup>13</sup>
- **House of Common Science and Technology Committee Inquiry into Genomics and Genome Editing in the NHS** - The House of Commons Select Committee on Science and Technology launched an inquiry into ‘Genomics and Genome Editing in the NHS’ in 2017. The inquiry examined the Chief Medical Officer’s call in her 2016 annual report ‘Generation Genome’, for mainstreaming genomic medicine in the NHS within 5 years. The Committee’s Third Report of Session was published in April 2018 and the Government response was published in July 2018. A full list of publications, including written and oral evidence can be viewed [here](#)<sup>14</sup>:

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<sup>9</sup> <https://www.abi.org.uk/data-and-resources/tools-and-resources/genetics/genetics-faqs/>

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<sup>11</sup> <https://www.abi.org.uk/Insurance-and-savings/Topics-and-issues/Genetics>

<sup>12</sup> <http://www.geneticalliance.org.uk/information/living-with-a-genetic-condition/insurance-and-genetic-conditions/>

<sup>13</sup> <http://bma.org.uk/practical-support-at-work/ethics/confidentiality-and-health-records>

<sup>14</sup> <https://www.parliament.uk/business/committees/committees-a-z/commons-select/science-and-technology-committee/inquiries/parliament-2017/genomics-genome-editing-nhs-17-19/>