



The changing landscape of genetics and insurance in the UK

Report from a workshop organised by the British Society for Genetic Medicine and the Centre for Personalised Medicine

November 2024



BACKGROUND

There is a long-standing concern that people might be treated differently or in some sense unfairly because of their genetic background. This might involve being denied access to insurance or being offered lower coverage or higher costs. People may also avoid genetic testing, even where this might be beneficial (e.g. to access extra screening), because of how they perceive it might affect their insurance. On the other hand, if insurance companies cannot use any genetic information to price their policies, this could lead to price increases or unavailability of certain types of insurance plans. Insurers might exit from parts of the market.

The UK's Code on Genetic testing and Insurance ('the Code') applies to life, critical illness and income protection policies. Reports on the Code show that, to date, genetic information has not had wide-ranging impacts on insurance decisions in the UK. There are, however, many examples of individuals experiencing difficulties in accessing affordable insurance. Furthermore, there is a strong case for considering if the current arrangements are fit for purpose because of expansions in the scale, speed and sophistication of genetic testing over the last few years. Alongside this, the Department of Health and Social Care launched a call for evidence in 2023 to seek views on the Code and to explore whether it needs to be revised to ensure it is fit for purpose.

This report summarises the discussions at a workshop on the changing landscape of genetics and insurance in the UK. The focus was on existing and emerging issues that might challenge current arrangements in the UK about how genetic information can, and should, be used for insurance purposes. More than eighty participants attended the workshop which was organised by the Centre for Personalised Medicine (CPM), University of Oxford and the British Society for Genetic Medicine (BSGM) and took place on May 15th 2024. Participants included representatives from healthcare, patient organisations, the Department of Health and Social Care, the Association of British Insurers and academia. The background information provided to the workshop participants can be found here:

<https://cpm.ox.ac.uk/genetics-and-insurance-complexities-in-the-genomic-era/>

There were four invited presentations on a range of topics and from a variety of perspectives:

PRESENTATIONS

- **Dr Ana Hallgarten la Casta**, Department of Health and Social Care, “The Code and the 2023 consultation”
- **Sophie Peet**, Genetic Alliance, “A summary of patients' and families' experiences and concerns”
- **Dr Pdraig Dixon**, University of Oxford, “Genetics and Insurance in the UK: Increasing complexity and emerging challenges”
- **William Meredith and Rebecca Ward**, Association of British Insurers (ABI), “Insurance industry perspectives”

The presentations were followed by a question-and-answer panel session involving all the speakers. This was followed by a facilitated discussion which focused on whether the current Code needs to change to be both clear and fair in 2024 and beyond. The key points of both these sessions were as follows:

- **Clinical, scientific, and technical developments:** Since the original version of the Code came into effect in 2001, there have been a range of scientific and technical developments which have led to some changes in practice. These developments mean it is sometimes unclear how to apply the Code to today's practice. There was an acknowledgement that patients, clinicians, insurers and wider publics do not always understand what the implications of genetic testing might be for insurance. It was noted that genetic testing is increasingly used to inform treatment decisions in cancer, and these test results may also have implications for the patient's family members. For example, an individual with breast cancer may have diagnostic genetic testing to inform their decision about chemotherapy; if a *BRCA 1/2* variant is found, this may be relevant in prediction of cancer risks for close family members.
- **Discouraging genetic tests:** Anecdotal reports were shared of patients deciding against having (and family members advising their relative *not* to have) a genetic test for cancer risk variants, because of the fear of negative implications for their insurance. There was a strong consensus that addressing such concerns in future developments of the Code or other future forms of regulatory oversight was important. For example, in the context of rare conditions like von Hippel-Lindau (VHL), the inability to obtain insurance reported by patient representatives stems in

part from misperceptions about how the condition might affect people. The unpredictable nature of VHL leads to varied presentations among individuals. This raises concerns that being "diagnosed" means being uninsurable, especially since many individuals diagnosed with VHL may be more mildly affected by the condition. The group stressed the importance of not discouraging genetic testing where clinically indicated, as such testing aligns with (for example) the NHS's long-term goal to identify and manage cancer early.

- **Understanding within the insurance industry:** Several strands of discussion asked whether insurance underwriters had sufficient understanding of genetics and the sometimes uncertain risks associated with results. It was noted that specialist genetics underwriters, medical advisors, and brokers are available in specific circumstances. But it was unclear how and whether potential customers could access these specialists and how their advice influenced the use of genetic information by insurance companies.
- **Treatment of genetic data in comparison to other data:** There were concerns about the ways in which genetic data are privileged, or may be privileged, over other types of medical data in insurance. For example, there was concern that increased use of genetic testing to determine insurance premiums could promote a more deterministic perspective of disease, which may undermine efforts to highlight the multifactorial nature of many common diseases and thus the ability to reduce risks through interventions such as smoking cessation.



- **Calls for greater transparency:** There was agreement that more information is needed on how the Code operates. There was a call for more transparency in insurance practices, especially concerning the rates of payout for those with rare conditions. A proposal was made that every insurance provider should report how many people are turned down or have higher premiums based on the results of their genetic tests and/or their family history. It was acknowledged that any disclosure/reporting framework would need to consider competition law.
- **Distinguishing between diagnostic and predictive testing:** The Code defines and distinguishes between diagnostic and predictive tests. There was a discussion about whether this distinction is useful. For example, the discussion highlighted a (possible) lack of awareness about the Code's definition of these tests among healthcare professionals, including when it does/does not apply to a particular situation. Certain diagnostic tests may also be predictive, highlighting the need for more widespread training and education about these matters. For instance, a woman with breast cancer may undergo diagnostic testing for cancer-predisposing variants to inform her treatment options. Particular *BRCA* variants are however also predictive of a future risk of ovarian cancer. As testing becomes more frequent as part of treatment decisions, the likelihood of identifying predictive information for additional conditions increases.
- **Variants of uncertain significance:** Today's more granular genetic analyses can identify variants that are neither clearly benign nor clearly disease predisposing. These are known as variants of uncertain significance (VUS). Variants currently classified as VUS may be shifted into the category of either (likely) pathogenic or (likely) benign as further clinical and/or research evidence is gathered so that genetic results evolve over time. A VUS may become predictive, diagnostic or neither of these categories.
- **Identifying variants with reduced penetrance:** When the code was first introduced, genetic testing was often only offered to those with a very strong family history of a condition. In this context, where *BRCA 1 or 2* variants were identified they were thought to confer up to a 95% lifetime risk of cancer. As such testing has expanded to population settings, it has become clear that the penetrance of such variants in the absence of a relevant family history can be less than 50%; that is, a finding of such a variant in a person without a family history of relevant cancers is substantially less predictive of future disease risk. Nevertheless it was thought that

decisions about managing risk are often made on the basis of having found a genetic variant, without considering the context in which it was found. This raised concerns about labeling individuals as having disclosable information, potentially affecting their insurance and other aspects of their life, when they may never develop the condition in question.

- **Family history:** There was discussion about whether genetic testing contributes significant clinical value beyond family and personal medical history. This raised the question of when the discovery of a genetic variant would constitute a diagnosis and when a prediction.
- **Polygenic Scores:** These were discussed as another type of genetic test that could provide a prediction, but often in absolute terms not a very strong one. There was discussion about when and how weak predictions can and should influence insurance decisions.
- **Urgent test-treatment decisions:** Concerns were raised regarding the potential impact of urgent test-treatment decisions. Genetic testing in this context allows little, if any, time to discuss the possible implications for future insurance applications.
- **Discrimination:** A concern was voiced that the wide availability of genetic tests might lead to increased discrimination, as genetic risks are not unique—everyone has some risk for certain conditions. If genetic risks are treated differently to other risks that influence insurance underwriting (and the Code creates such a difference), then inevitably there will be “winners and losers.”



- **Implications of direct-to-consumer genetic testing:** There was discussion about how individuals may opt for direct-to-consumer genetic tests to avoid results being recorded in their health care records because of concerns about the impact on insurance. Such tests have been reported as having both a high false positive and false negative rate, so this practice might adversely affect their clinical care (see, for example, Horton et al: <https://doi.org/10.1136/bmj.l5688>)
- **Concerns about adverse selection:** The rising use of genetic testing could make insurance more costly or harder to get. As more people get genetic tests that label them as high-risk, some might buy insurance without revealing their risks if not obliged to do so under the provision of the Code. This would make it difficult for insurers to predict claims accurately, which could lead to more claims than expected, potentially destabilizing the insurance market. This would be an example of adverse selection. Insurance needs to stay affordable and accessible for consumers, with choices and fair competition. However, if the risk level of average customers goes up because of adverse selection, insurers may need to raise premiums. This could lead to pricier, exclusive options that many people cannot afford. On the other hand, allowing genetic information in underwriting could potentially (but not necessarily) make insurance more efficient and lead to lower average costs. However, this could create big cost differences among individuals, favouring those with “genetically fortunate” profiles. This raises ethical concerns about fairness in risk-sharing. There is still a lack of evidence over how much these issues would actually impact the UK insurance market.
- **Huntington’s Disease (HD)**

The only condition for which insurers may currently request disclosure of a predictive genetic test result is for HD in applications for life insurance cover over the financial limit of £500,000. This raises concerns about singling out HD. Although HD is often used as a quintessential example of a fully penetrant dominant condition (everyone with the genotype will get the disease), some forms of the ‘HD-causing’ genotype have incomplete penetrance and will not necessarily lead to a person developing the condition. This means that even in the case of HD it can be difficult to predict when and if a person will develop the condition. Furthermore, cases were cited during the meeting where those with a family history of HD who have undergone predictive tests and do not carry the HD expansion, or even [not biologically related] spouses of affected individuals, have faced increased premiums. The sum of £500,000 as the

limit of/for life insurance has not changed since the first version of the Code was drawn up in 2001. There was some discussion concerning possible increases to this limit.

SUMMING UP THE DISCUSSION

Different agendas were noted—technological, governmental, and commercial—that influence the push for broader genetic testing, sometimes without the utility of these different agendas being made clear. There was a call for objective evidence on who is being turned down or dissuaded from getting insurance and a suggestion to collect anonymous data on existing policyholders' experiences with disclosure. Concerns were raised about how consumers and insurers interpret genetic information, noting that both may struggle with risk assessment. The role of medical reviewers in insurance decisions was discussed, with a suggestion for independent reviewers to ensure fairness and minimize bias.

In summary, there was agreement that there was a need for clearer definitions and better data to navigate the complex interplay between genetic testing and insurance, ensuring fairness, accessibility and understanding for consumers and insurers alike.

*Report prepared by: Padraig Dixon, Tara Clancy, Susie Weller and Anneke Lucassen
Please contact cpm@well.ox.ac.uk with any comments or queries*





CENTRE *for* PERSONALISED MEDICINE

St Anne's College, Woodstock Road,
Oxford, OX2 6HS, United Kingdom

Centre for Human Genetics, Roosevelt Drive,
Oxford, OX3 7BN, United Kingdom

BRITISH SOCIETY *for* GENETIC MEDICINE

1 Naoroji Street, London, WC1X 0GB,
United Kingdom