

**The Data Protection and Digital  
Information Bill:  
A dangerous loss of personal control over  
genetic information**



**December 2023**

The Data Protection and Digital Information Bill is currently being discussed in parliament. It removes the safeguards that currently apply to people's genetic information. **If the Bill is passed, everyone in the UK will lose control over how their genetic information is shared and used.** This could create a 'surveillance state', in which every individual and their relatives can be tracked using their DNA. People's genetic information would be open to commercial exploitation and to security risks resulting from misuse by foreign governments.

For more information, including a detailed briefing for MPs and peers, see:  
<http://www.genewatch.org/sub-578247>

**What is genetic information and how is it protected?**

Genetic information is obtained by analysing your DNA, collected from your saliva, a hair root, or a sample of your blood. Your genetic information is unique to you and can be used like a 'genetic fingerprint' to identify you by matching it on a computer database which stores your name and genetic information together. Because most people do not currently have their genetic information stored, most people can't be identified like this today. But this is changing because: (i) genetic databases are getting bigger, as more people buy ancestry tests, take a medical genetic test, or give their genetic information for research; (ii) a partial match with a relative's genetic information could be enough to identify you, even if you are not on a database yourself, and; (iii) your identity can be deduced if it is combined with other information, such as a medical diagnosis or part of your postcode, and this is getting easier as computers get faster and databases grow.

Your genetic information can also be used to deduce anything that may be (partially) inherited, such as your surname, health conditions, 'genetic ancestry', or appearance, as well as who you are related to. Some of these deductions may be wrong but they could still be used to discriminate against you. Comparing your genetic information with that of relatives can also reveal non-paternity.

**How do the proposals in the Bill change this?**

Currently, all genetic information is classed as 'personal information' and is covered by data protection law. Because it is particularly sensitive, extra safeguards apply. The Bill rips up the current safeguards for genetic information. Some genetic information will no longer be classed as 'personal data' and thus will have no safeguards at all. Other genetic information will still count as 'personal data' but individuals will still lose control over how it is shared and used.

### **Some genetic information will have no safeguards at all**

Under Clause 1 of the Bill, information that cannot be identified “at the time of processing” will no longer be treated as personal information, so it will be exempt from data protection laws. This means that your genetic information could be shared with anyone, including commercial companies and foreign governments, provided it doesn’t have your name (or other personal identifiers) attached. As genetic databases grow, you are likely to become identifiable from your genetic information at a later date, but by then it will be too late to get your genetic information back.

### **You will lose control over how all your genetic information is shared and used**

Some genetic information will still be treated as ‘personal information’, i.e., if it can be identified at the time of processing. This is clearly the case if your genetic information has your name or an identifier such as your NHS number attached. This genetic information will still be covered by data protection laws. However, the Bill proposes weakening these laws, so you will have little or no control over how your genetic information is shared or used. In addition, the Government will allow genetic information to be shared abroad as long as foreign governments meet the same low standards of protection. This means:

- You will no longer have any say over the types of research that your genetic information can be used for, or who has access to it. Commercial companies or foreign governments could research new ways to exploit your DNA without you being told.
- The police and security services will no longer have to go to court if they want access to genetic databases, they will be able to access your genetic information as a matter of routine.
- You will lose the right to know how your genetic information is being used, so you won’t be able to stop misuses because you won’t be able to find out about them.
- The Government will be able to weaken the law even further in the future, without proper parliamentary scrutiny.

### **What could possibly go wrong?**

Genetic information allows individuals and their relatives to be identified and tracked, like a ‘genetic fingerprint’. Since it is expected to be shared internationally, individuals (including political dissidents, for example) could be tracked down wherever they are, and their relatives could also be identified and targeted. Vulnerable people (such as people on witness protection schemes or fleeing domestic violence) could have their identities exposed and be tracked by their abusers, as could undercover police officers or security service personnel. Women and children could be put in danger if non-paternity is exposed, families could be broken up, and powerful people could be blackmailed if children born outside marriage can be identified. In addition, categories derived from statistical analysis of genetic data (such as ‘genetic ancestry’, predicted health risks, or claimed genetic propensities to certain behaviours) can lead to stigma and discrimination. This might lead to people being refused insurance or a job, or even to attacks on groups of people based on their ‘genetic ancestry’. Genetic information can also be exploited for misleading marketing because genetic testing is not regulated. Companies make their own interpretations of what a person’s genetic information means for their health, with no independent checks.

### **Isn't sharing genetic information important for medical research?**

Some medical research does rely on sharing genetic information. But the proposals in the Bill are a threat to legitimate genetic research. This is because:

1. People will only share their DNA with researchers if they can trust that it is only being used for the purposes that they agreed to. This is known as “fully informed consent”. Usually, people want some limits on commercial exploitation and on access by the police. Promises that have been made to people already taking part in some genetic research projects would be broken under the proposed new law.
2. The proposals create a risk that other countries will stop sharing genetic information (and perhaps other information) with the UK. This is because the removal of important safeguards means genetic information shared with the UK will not be safe. For example, the USA doesn't want its citizens' genetic information to be shared with China, but this could not be guaranteed in future.

### **Whose genetic information is affected?**

If the Bill is passed, it will affect anyone living in the UK or using the NHS.

In the short term, people who have given their DNA to research projects such as UK Biobank, the National Institute for Health and Care Research (NIHR) Bioresource, Genomics England or Our Future Health, will be the first to be affected. This is because the safeguards that currently apply to their stored genetic information will no longer be legally required. The same applies to customers of companies selling genetic tests online, such as 23andMe and Ancestry. For example, promises that the police will only be given access to these databases if they have a court order will not be able to be kept.

In the longer term, everyone using the NHS will be affected, as more people have genetic tests as part of their health care or in new research or screening programmes. A pilot project, led by Genomics England, is expected to start collecting genetic information from babies in the NHS beginning in 2024, with a view to screening every baby's whole genetic make-up at some point in the future. For more than 50 years, every newborn baby has a heel prick of blood taken at birth for some important medical tests and millions of these blood samples are still stored by hospitals. In the future, without proper safeguards, genetic information could be collected from these blood spots to create a DNA database within the NHS. The proposals in the Bill could lead to commercial exploitation of this DNA, access by foreign companies and governments, and the creation of a 'surveillance state' in the UK.

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