



Information Commissioner's Office
Promoting public access to official information
and protecting your personal information

House of Lords Science and Technology Committee

Call for evidence: genomic medicine

Evidence submitted by the Information Commissioner

1. The Information Commissioner has responsibility for promoting and enforcing the Data Protection Act 1998 and the Freedom of Information Act 2000. He is independent from government and promotes access to official information and the protection of personal information. The Commissioner does this by providing guidance to individuals and organisations, solving problems where he can, and taking appropriate action where the law is broken. The comments in this evidence are from the data protection perspective. They focus on the questions raised about the implications of the generation and storage of genome data on personal data security and privacy, and on its potential use or abuse in employment and insurance.
2. The Commissioner recognises that recent developments in genomic medicine are leading to major advances in the understanding and detection of genetic related diseases and medical conditions. These advances have the potential to lead to significant improvements in medical treatment and health care. However there is a risk that these potential benefits will not be fully realised if people have concerns about the potential misuse of their personal information. Organisations must ensure that robust safeguards are in place so that individuals enjoy a proper level of privacy and data protection and their personal genetic information is handled in a way that inspires trust. This is essential if people are not to be put off participating in genetic research or taking genetic tests that may be beneficial for their health by the fear that their personal information may be misused.

Implications of the generation and storage of genome data on personal data security and privacy

3. Advances in genetic technology mean that huge amounts of detailed genetic data are now being obtained and processed. As more information is held there is growing concern about the effects on individual privacy and whether sufficient safeguards are in place to protect personal information. The greater the numbers of databases that contain genetic information, the greater the likelihood of people being able to link and match information, which could in time lead to the identification of individuals or members of their families. Indeed, some question whether it will be possible in future to ever maintain anonymity of genetic information. While these risks may be largely theoretical at present, technological advances are likely to increase the likelihood of this happening in future. Other concerns include whether an individual can give informed consent for the use of their genetic personal information when there is so much uncertainty about how their information may be used in future, especially if the information is widely

shared and retained indefinitely. While the sharing of genetic information is likely to produce benefits for society in terms of understanding and treatment of genetic diseases, this has to be weighed against risks to the individual in terms of breaches of privacy and misuse of their information.

4. The Commissioner does not underestimate the significant challenges ahead to ensure that the application of the Data Protection Act, particularly as regards information security and rights to privacy, keeps pace with the technological advances in genomic medicine. The Commissioner believes that conducting privacy impact assessments offers organisations and individuals significant benefits by ensuring that privacy concerns and safeguards are addressed and built in from the outset of any project. He is also concerned that the best use is made of privacy enhancing technologies wherever possible to protect personal data.

Potential for use or abuse in employment and insurance decisions

5. We understand that genetic testing has the potential to provide employers and insurers with information that is predictive of the likely future general health of individuals or with information about their genetic susceptibility to certain diseases. Genetic testing is still developing and in many cases has an uncertain predictive value. Although there are many diseases with a recognised genetic component resulting from a defect from a single gene (monogenic diseases), for example Huntington's chorea and cystic fibrosis, the incidence of these diseases is very low. In contrast the incidence of diseases resulting from interactions between several genes (polygenic diseases) appears to be much higher and tests for these are far more likely to be of interest to employers and insurers. Apparently, in most of these cases, the genetic basis is incompletely understood and is complicated by influences of environment, diet and lifestyle. Indications that an individual may have a genetic susceptibility to conditions such as type 2 diabetes, heart disease or obesity may be acceptable for making decisions about medical treatment but there may be unfairness in basing insurance or employment decisions on an inexact genetic test especially when a multiple number of factors are at play.
6. We gather that, even for monogenic diseases, the predictive value of genetic testing may be limited. There is always the possibility that the disease in question might not manifest itself during the working life of an individual and it is not always possible to predict the severity of the future disease. The situation is even more complex where diseases with a polygenic basis are concerned. We understand that at the present time it is virtually impossible accurately to predict, using genetic tests, either whether the disease will develop at all or, if it does, its timing and severity. Even if the genetic basis of such disease becomes fully understood, environmental and lifestyle factors, which may themselves be unpredictable, will limit the predictability of disease development.
7. The Commissioner has provided specific advice to employers on the use of information from genetic tests in his Employment Practices Code and Supplementary Guidance. These advise that very few genetic tests are available at present that give information that could validly be used in the context of

decisions concerning employment. However, the number of genetic tests is increasing rapidly and as genetic technologies improve, it is likely that this situation may change in future although it is difficult to assess the pace of change. At the present time, the validity of a genetic test would require demonstration of: its relevance to health protection of workers; the reliability and reproducibility of the test; and the level of predictive value for the test. It is particularly important that procedures for genetic testing are as reliable as possible, as provision of incorrect information could have far reaching consequences for individuals.

8. The Data Protection Act 1998 requires that all processing of personal information should be fair and lawful and the information should be accurate, of good quality and up to date. Our general approach to decision-making is that it is likely to be inherently fairer if decisions are drawn from accurate information about the individuals concerned. However if advances in genetic testing make it possible to predict accurately someone's lifespan or length of working life, it raises the question of whether those with poor prospects should pay commensurately higher insurance premiums and be less attractive to employers. We believe that it will be for society as a whole to address the broad questions of whether society should be sharing the cost of insurance and whether there is a need to restrict the use of predictive genetic testing for employment purposes.

The extent to which genetic information has implications for relatives

9. The Commissioner recognises that very complex privacy issues are involved when genetic information about one person could reveal information about other blood relatives. For example, sometimes the results of genetic tests may suggest that relatives should be receiving medical care and ought to be alerted to the fact. This raises difficult questions about individual confidentiality for which there are no simple answers. We consider that this is an area where there is a need for some form of code of practice or guidance to be developed by health professionals.
10. In conclusion, the Commissioner considers that it is vital that the public has trust and confidence in the organisations that hold very sensitive personal information about them. Clearly developments in genomic medicine are enabling us to build up more detailed information about individuals and this has to be protected properly. This strengthens our arguments for increased audit and inspection powers for the Commissioner, along with more effective penalties for serious disregard for the requirements of the data protection principles.

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