

Submission to the Review of the Privacy Act 1988 (Cth) - genetic and genomic data

Australian Government: Attorney-General's Department

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Contributing Authors

Dr Caitlin Curtis

c.curtis@uq.edu.au

Dr James Hereward

j.hereward@uq.edu.au

Dr Giselle Newton

giselle.newton@uq.edu.au

This submission represents the opinions of the contributing authors listed in this document. It does not necessarily represent an official position of The University of Queensland.

Introduction

This submission responds to the Privacy Act Review Report¹ as part of the Review of the Privacy Act 1988 (Cth). Our submission and recommendations specifically relate to whether the Privacy Act effectively protects personal information and provides a practical and proportionate framework for promoting good privacy practices the scope and application of the Privacy Act: emphasis on 4.7.1 “Updating existing categories of sensitive information: Genetic and genomic information”, matters within our areas of specialist expertise.

Background and Recommendations

4.7.1 Updating existing categories of sensitive information: *Genetic and genomic information*.

As noted in the Privacy Act Review Report genetic and genomic information represent an important category of sensitive information which, like biometric information, is unchangeable and impossible to recover or protect once compromised. We support the proposal to update existing categories of sensitive information to include both genetic and genomic data as sensitive data.

The size of genomic databases is rapidly increasing. Genomic data may be generated in a medical context, but this data also has ‘secondary’ usefulness outside of the clinic^{2,3}. Genomic databases created in medical and research contexts may experience increasing access queries for other uses from outside agencies such as forensics, immigration, and commercial entities. Increasingly, genetic and genomic data is being generated by commercial genetic testing companies relating to ancestry, health and commercial forensic services. With the move towards whole genome sequencing the various competing interests for genetic data are going to come into increasing friction.

However, genomic and genetic data are a special case of data that deserve greater protection than other types of sensitive data for the following reasons:

- 1) Genetic data is incredibly difficult to de-identify⁴. Many experts argue that genetic data is inherently identifiable⁵.
- 2) Genomic data is highly predictive of behavioural and mental health traits, and future health. The predictive nature of genomic data raises concerns about the right to non-discrimination and equal treatment – including for children.
- 3) Genetic data impacts both the privacy of the individual as well as that of many distant relatives across generations, including those not yet born (for example, publicly releasing genetic data can enable the identification of up to 190 third cousins)⁶. As such, genomic data presents unique concerns about the right to privacy for individuals, particularly those individuals who did not consent to genetic testing or other use and/or access to their genetic data. Further, privacy implications increase as the size of genomic databases increases because people can be identified via their distant relatives in largescale genomic databases, such as those used in ancestry testing. For example, an estimated 60 per cent of people in the US of European descent can be traced by the same type of “long-range familial searches” that were used to identify the Golden State Killer suspect in the United States⁷.

Based on these unique attributes, genetic and genomic data require additional protection to uphold the human rights of individuals and families. In particular, the shared familial nature of DNA data means that issues around privacy relating to this data need to be addressed by communities or society rather than by individual decisions.

These are not new issues. In 2003 the Australian Law Reform Commission and Australian Human Ethics Committee of the NHMRC released a 1000-page report (Essentially Yours: The Protection of

Human Genetic Information in Australia (ALRC Report 96))⁸ containing 144 recommendations, many of which have not been actioned 16 years later.

Genetic data requires specific legislation. Current legislation is insufficient, and technology is progressing faster than Australian law. We suggest that Australia should enact a Genetic Data Protection Act providing specific protection for genetic and genomic data⁹.

In summary:

- Genetic and genomic data are highly identifying and predictive and affect both individuals, families, and communities.
- Genetic and genomic data require additional protection compared to other forms of sensitive information.

Recommendation 1: The Privacy Act 1988 (Cth) must recognise genetic and genomic data as the most sensitive category of information.

Recommendation 2: The Privacy Act 1988 (Cth) should advocate for additional protections for genetic and genomic data by declaring that they are a special type of sensitive data and that they deserve specific protection and regulation.

Contributing authors

This submission has been written by the following authors at The University of Queensland:

- **Dr Caitlin Curtis**, Research Fellow, Centre for Policy Futures; Lecturer, School of Business; Affiliate Research Fellow, School of Public Health, The University of Queensland
- **Dr James Hereward**, Research Fellow, School of Biological Sciences, The University of Queensland
- **Dr Giselle Newton**, Postdoctoral Research Fellow, Digital Cultures and Societies, The University of Queensland; Adjunct Associate Lecturer, Centre for Social Research in Health, UNSW Sydney

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