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SUBMISSION TO THE HUMAN RIGHTS AND TECHNOLOGY PROJECT

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Part B: Submission
Human rights and technology

1. What types of technology raise particular human rights concerns? Which human rights are particularly implicated?

Genomic data is highly predictive and it provides information about not only the sample donor, but also family members, including distant relatives and future generations. 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. The predictive nature of genomic data raises concerns about the right to non-discrimination and equal treatment – including for children.

Genetic data requires specific protection because it is:

- Highly predictive of future health
- Predictive of behavioural and mental health traits
- Highly unique to an individual and therefore highly identifiable
- Difficult / impossible to keep anonymous
- DNA is shared with family members

Genomic data may be generated in a medical context, but this data may have ‘secondary’ usefulness outside of the clinic. Access to 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 even commercial forensic services. With the move towards whole genome sequencing the various competing interests for genetic data are going to come into increasing friction, and we believe genetic data requires additional protection to ensure that this does not negatively impact human rights.

Reinventing regulation and oversight for new technologies

3. How should Australian law protect human rights in the development, use and application of new technologies? In particular:

a) What gaps, if any, are there in this area of Australian law?

Genetic data requires specific legislation. Technology is progressing faster than Australian law. Current legislation is insufficient and we suggest that Australia should enact a Genetic Data Protection Act providing specific protection.

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)*) containing 144 recommendations, many of which have not been actioned 16 years later. This demonstrates a slow response to developing technologies that has resulted in an urgent need for action now. Recent technological advances mean that right now we are generating substantial amounts of genetic data and the lack of sufficient legal protection is especially acute. There is a need for public consultation on the benefits and risks of new technology before they are widely used.

b) What can we learn about the need for regulating new technologies, and the options for doing so, from international human rights law and the experiences of other countries?

The following international efforts provide good examples:

- In 2001 the UK introduced a moratorium on the use of genetic information by the life insurance industry. We note that a moratorium in Australia was proposed by the Australian Joint Parliamentary Committee on Corporations and Financial Services following an Inquiry into the Life Insurance Industry, the [report of which](#) was released in March 2018. A moratorium has not yet been put in place.
- In 2008 the USA introduced the Genetic Information Non-Discrimination Act. This Act introduces legislation that is, in the most part, covered under Australia's *Disability Discrimination Act 1992*.
- Several EU countries also have specific genetic legislation,
- In 2018 the European Union approved the General Data Protection Regulation, which followed four years of preparation. In particular, the regulation addressed new conditions for consent and penalties for organisations in breach of the GDPR.

The International Bioethics Committee of UNESCO has created three Declarations:

- Universal Declaration on Human Genome and Human Rights
- International Declaration on Human Genetic Data
- Universal Declaration on Bioethics and Human Rights

Many of these recommendations need to be enacted into domestic law to provide meaningful protection.

c) What principles should guide regulation in this area?

The guiding principles are largely set out in the ALRC Report ('Essentially Yours') and UNESCO Declarations. What is required now is the translation of these principles and recommendations into law.

4. In addition to legislation, how should the Australian Government, the private sector and others protect and promote human rights in the development of new technology?

Legislation is an important part of the solution. Education, technology, and the provision of a clear mechanism for making complaints will also be very important for protecting genetic data.