

# Review of the Privacy Act 1988

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**Submission**

**Population Health Research Network**

**10 January 2022**



# ABOUT THE PHRN

The Population Health Research Network (PHRN) is a national data linkage infrastructure network. The PHRN commenced in 2009 and is funded by the Australian Government's National Collaborative Research Infrastructure Strategy (NCRIS), with support from state and territory government agencies and academic partners. The University of Western Australia is lead agent for the PHRN. The PHRN's primary purpose is to build and support the operation of collaborative, nationwide data linkage infrastructure capable of securely and safely linking data collections from a wide range of sources including within and between jurisdictions and across sectors and providing access to linked data<sup>1</sup>.

## Our Roles

- We are a respected, independent and trusted broker, valued for bringing governments, organisations, individuals and data together securely.
- We collaborate to enhance and maintain significant, innovative research infrastructure to improve the nation's data linkage capability.
- We facilitate and grow the use of linked data in the areas of health and human services.
- We advocate for an improved authorising environment for better access, use and sharing of data.
- We support the whole of government focus on accessing, sharing and using data for the national good.

## Our Vision

Linking life data to improve the wellbeing of all Australians

## Our Mission

To lead and enable the linking of data for world class, action-oriented research

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<sup>1</sup> Flack, F. and Smith, M. (2019) "The Population Health Research Network - Population Data Centre Profile", *International Journal of Population Data Science*, 4(2). doi: 10.23889/ijpds.v4i2.1130.

# PHRN RESPONSE TO THE CONSULTATION

## Introduction

The PHRN is pleased to have the opportunity to contribute to the Review of the Privacy Act. The PHRN funds, supports and coordinates a national research infrastructure which links and shares person-level health and human services data for research in the public interest. Information privacy and the balancing of privacy interests against other interests and rights is central to the work that we do.

Although this review does not explicitly include the way the Privacy Act impacts on access to data for research some of the proposed changes will affect the use of data for research. These changes are the focus of this submission. In addition, given the extensive nature of this review, there may be opportunities to make some additional changes to the Privacy Act which would assist research in the public interest.

## Research and the Privacy Act

There are a number of recommendations about research and the Privacy Act made by the Australian Law Reform Commission (ALRC) which have never been implemented but are still strongly supported by the PHRN.<sup>2</sup>

Sections 16A and 16B of the Privacy Act deal with ‘permitted general situations in relation to the collection, use or disclosure of personal information and health information respectively. One of these permitted purposes is research, specifically medical research or research relevant to public health or public safety. The PHRN strongly agrees with the ALRC that this “should be extended to cover all human research”. This would enable a much broader range of research in the public interest to be conducted including in important areas such as education, justice and child protection.

Sections 95 and 95A provide for guidelines to be made by the CEO of the National Health and Medical Research Council and approved by the Commissioner in relation to research. These two sets of non-identical guidelines are inconsistent and confusing. We support the ALRC recommendation that there should be only one set of research guidelines or rules.

The PHRN strongly recommends that these two changes, which have been proposed for more than 10 years, are finally made to the Privacy Act.

## Privacy and Other Interests and Rights

The objects of the Act and whether it remains appropriate to balance the protection of privacy against other public interests is raised in the discussion paper. The PHRN agrees with the proposal that the Act be amended to clarify that it is about informational privacy rather than

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<sup>2</sup> For Your Information: Australian Privacy Law and Practice, ALRC Report 108, Vol 3 Part H 65. 2008

privacy per se. In addition, we agree that the Act should recognise the importance of balancing individual interests in privacy with other individual and public interests and rights including:

- the right to enjoy the highest attainable standard of physical and mental health (UN ICESCR art 12)<sup>3</sup>
- the right to enjoy the benefits of scientific progress (UN ICESCR art 15)<sup>4</sup>

## Personal Information

The determination of whether data is ‘reasonably identifiable’ has always been difficult but has become increasingly difficult in recent years because of new types of data, the increasing volumes of data generated and the technical capability to manage and analyse this data. Therefore, this is an important topic for the Privacy Act Review. The PHRN agrees that the definition of personal information should be reviewed. We would also propose that the current binary approach to dealing with privacy issues, consent or anonymise/de-identify, is no longer fit for purpose. There is now extensive literature on the difficulties of informed consent as well as the virtual impossibility of achieving true anonymisation given the volume of data and the technology available to analyse it.<sup>5</sup>

The PHRN’s responses to the specific proposals in the Discussion Paper about personal information are listed below.

### *2.1 Change the word ‘about’ in the definition of personal information to ‘relates to’.*

The PHRN support the proposed change to the definition of personal information.

### *2.2 Include a non-exhaustive list of the types of information capable of being covered by the definition of personal information.*

Whilst a non-exhaustive list would be helpful in understanding the types of information covered by the definition, some caution should be exercised in compiling the list as it will likely be interpreted as a definitive list.

### *2.3 Define ‘reasonably identifiable’ to cover circumstances in which an individual could be identified, directly or indirectly. Include a list of factors to support this assessment.*

It is unclear why the proposed definition of ‘reasonably identifiable’ would be useful as it will be very difficult to implement and will continue to embed the consent or anonymise dichotomy in the Act.

Identifiability occurs on a spectrum and is not an intrinsic characteristic of the data.

A number of factors influence the identifiability of data including the:

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<sup>3</sup> International Covenant on Economic, Social and Cultural Rights 1966

<sup>4</sup> *ibid*

<sup>5</sup> Adams C, Allen J and Flack F. Sharing linked data for health research: Towards better decision making. Cambridge University Press. Chapter 2. In Press.

- type of information e.g. overt identifiers such as name, address and date of birth
- quantity of information
- the nature of the participant cohort e.g. inclusion of high profile individuals
- methods of statistical disclosure control used
- other information held by person who receives it (the information itself does not need to be intrinsically identifiable. Extrinsic material held by the recipient should also be considered)
- skills and technology of person who receives it.

All data relating to an individual should be covered by the Privacy Act. The focus of the Act should be on identifying risks of harm (not just risks of re-identification) as well as benefits associated with the collection, use and disclosure of personal information and the application of appropriate risk mitigation strategies e.g. removing overt identifiers, and appropriate information security measures. This approach would hopefully shift privacy practices from an emphasis on achieving de-identification/anonymisation in order to avoid having to comply with the Privacy Act to a focus on beneficial outcomes through improved data management and security.

*2.4 Amend the definition of 'collection' to expressly cover information obtained from any source and by any means, including inferred or generated information.*

The PHRN supports this amended definition.

*2.5 Require personal information to be anonymous before it is no longer protected by the Act.*

See above, all data relating to an individual should be protected by the Act. As discussed already, there are a range of issues around the concept of anonymisation and we think it is no longer a helpful concept. However, it may be necessary to define what type of information is not protected by the Act. This definition of information not protected by the Act would need to be the opposite of the definition of personal information e.g. data that does not relate to an individual.

*2.6 Re-introduce the Privacy Amendment (Re-identification) Offence Bill 2016 with appropriate amendments.*

At this stage, the PHRN is unable to support the re-introduction of the Privacy Amendment (Re-identification) Offence Bill without knowing the details of any proposed amendments. If this Amendment is to be re-introduced, it will be important for the research community to be consulted to ensure that it does not unnecessarily stifle research on cybersecurity and encryption which is critical to the continual improvement of the data security processes and technology used to manage sensitive data for research.

There should also be more discussion about inadvertent re-identification and the circumstances where this should not be considered an offence.

### *3.4 Amend the Act to permit organisations to disclose personal information to state and territory authorities when an Emergency Declaration is in force.*

The PHRN supports this proposal. For example, the disclosure of personal information from the Australian Immunisation Register to State and Territory governments to enable linkage with hospital and other health information can be critical for the management of a pandemic.

#### **Consent and Secondary Purposes**

We have concerns about proposal 9.1 “Consent to be defined in the Act as being voluntary, informed, current, specific, and an unambiguous indication through clear action”. This approach to consent is not as nuanced and flexible as the approach in the National Statement on Ethical Conduct in Human Research. We are particularly concerned that this may preclude extended or unspecified consent for the future use of data in research.

The PHRN is also concerned about the proposal to more narrowly define secondary purposes as “directly related to, and reasonably necessary to support the primary purpose”. This may also preclude a range of research of great value to the Australian people.

#### **Harmonisation of Privacy Laws Across Australian Jurisdictions**

The Discussion Paper proposes the establishment of “a Commonwealth, state and territory working group to harmonise privacy laws, focusing on key issues”. The PHRN links data across all Australian jurisdictions and is very familiar with the complexities and frustrations of working with data from all jurisdictions. Privacy law is just one part of the complex authorising environment for the use of data in research in Australia. We support attempts to harmonise privacy laws across Australia.

#### **Conclusion**

Access to person level data and the ability to link data about the same individual from multiple data sources is an essential component of health and human services research. Without access to this data, we cannot better understand and improve the health and wellbeing of Australians. The benefits of research should be balanced against individuals’ interest in informational privacy. The PHRN seeks to achieve and maintain this balance in everything that we do. Privacy laws are a key component of the authorising environment which must take into account a range of different interests and rights.

We are pleased to have the opportunity to contribute to this Review and would welcome further opportunities to assist in achieving the right balance between individual interests and the benefits of research.