

2021 REVIEW OF THE PRIVACY ACT

Submission in response to the Discussion Paper

December 2021

ABOUT RESEARCH AUSTRALIA

We are the national peak body representing the whole of the health and medical research pipeline.

Our vision: Research Australia envisions a world where Australia unlocks the full potential of its world-leading health and medical research sector to deliver the best possible healthcare and global leadership in health innovation.

Our mission: To use our unique convening power to position health and medical research as a significant driver of a healthy population and contributor to a healthy economy.

Our goals:

Engage

Australia in a conversation about the health benefits and economic value of its investment in health and medical research.

Connect

researchers, funders and consumers to increase investment in health and medical research from all sources.

Influence

government policies that support effective health and medical research and its routine translation into evidence-based practices and better health outcomes.

Nadia Levin

CEO & Managing Director

02 9295 8547

Nadia.levin@researchaustralia.org

www.researchaustralia.org

384 Victoria Street Darlinghurst NSW 2010

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Summary of recommendations

Research Australia notes the meaning of 'reasonably identifiable' is to be defined as 'capable' of being identified. On the face of it, 'capable of being identified' would appear to be a stricter test than 'reasonably identifiable', and inconsistent with the intention stated in the Discussion paper.

Further consideration should be given to how to provide guidance about the meaning of 'reasonably identifiable'.

Any process to consider the risk of identification of individuals from a dataset provided for research must assess the whole risk profile of doing so (likelihood and consequence) and the measures that can be put in place to mitigate the impact of reidentification. Simply assessing the likelihood of reidentification without considering the measures to mitigate the consequences of such an event is insufficient.

The implications for research of the proposed change to anonymisation must be considered in parallel with the further development of amendments to the Act.

An expert group should be formed specifically to work on the redevelopment of the NHMRC guidelines in parallel with drafting of proposed amendments to the Act.

The use of information for research purposes should be explicitly included in the considerations of any regulatory impact statement.

The Government should actively consult with the research sector on the Privacy Amendment Re-identification Bill before its reintroduction.

In particular, there should be further discussion about the circumstances in which reidentification would be an offence.

It is important to consider circumstances in which reidentification might be inadvertent, and also to support the reporting of reidentification to the provider of the dataset as a means of improving the security and anonymisation of data.

Research Australia supports the proposal to establish a Commonwealth, state and territory working group to harmonise privacy laws, and proposes that health information should be an area considered by the working group.

While we recognise that it is one of the most complex areas, it is also the area where both the public interest and the potential benefit to individuals is greatest.

2021 REVIEW OF THE PRIVACY ACT

Introduction

Research Australia is pleased to have the opportunity to make this submission, as the national peak body for Australian health and medical research, representing the entire pipeline from the laboratory to patient and the marketplace.

The Discussion Paper contains an extensive list of the matters to be considered. Research Australia notes that the list does not directly include the way the Privacy Act affects the use of information for research purposes.¹ Several of the proposed changes have implications for the way research is currently accommodated by the Privacy Act, and it is these changes which are the subject of this brief submission.

Research and the Privacy Act

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.

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. The Commissioner may only approve the guidelines if satisfied that the public interest in the use, disclosure or collection of the health 'substantially outweighs' the public interest in maintaining the level of privacy protection afforded by the Australian Privacy Principles.

The Guidelines have been in place for many years and were most recently updated in 2014. They assist researchers to understand how they can use personal information and health information in research, and guide Human Ethics Research Committees on how to assess the privacy aspects of research ethics applications.

¹ Research Australia acknowledges the Department established a webinar to consult stakeholders specifically on research and clinical secondary purposes, held on Thursday 16 December 2021. This submission has been informed by that consultation.

Privacy and the public interest

Research Australia notes the discussion in the paper about the objects of the Act and whether it remains appropriate to balance the protection of privacy against other public interests. We agree that the Act should not create a right to privacy, and support the proposal that the Act be amended to make it clear that it is concerned with informational privacy rather than privacy per se.

Research Australia supports the Discussion Paper's Proposal 1.1

1.1 Amend the objects in section 2A, to clarify the Act's scope and introduce the concept of public interest, as follows:

(a) to promote the protection of the privacy of individuals with regard to their personal information; and

(b) to recognise that the protection of the privacy of individuals is balanced with the interests of entities in carrying out their functions or activities undertaken in the public interest.

Deidentification and anonymisation

As the Discussion Paper notes, the definitions of 'personal information' and 'de-identified' determine the scope of the Act. These concepts have significant implications for the conduct of research using personal information and the concepts are addressed in the guidelines made under section 95 and 95A of the Act, referred to above.

Research Australia notes the Discussion paper proposes to amend the definition of personal information:

- to make clear that it includes technical and inferred personal information
- replace 'about an identified individual' with 'relates to an identified individual'
- define 'reasonably identifiable' to cover circumstances in which an individual could be identified, directly or indirectly.

Research Australia notes the meaning of 'reasonably identifiable' is to be defined as 'capable' of being identified. On the face of it, 'capable of being identified' would appear to be a stricter test than 'reasonably identifiable', and inconsistent with the intention stated in the Discussion paper.

Research Australia submits that further consideration should be given to how to provide guidance about the meaning of 'reasonably identifiable'.

The Discussion Paper also proposes replacing the current requirement that data be deidentified before the Privacy Act ceases to apply with a requirement the at the data be anonymised.

'If the definition of personal information is expanded then understandably more will need to be done to 'de-identify' that information so it falls outside that definition. The word 'anonymous' could more clearly signal to APP entities that they are required to meet the higher, irreversible standard reflected by this term.'

Information would be considered 'anonymous' if it were no longer possible to identify someone from the information, considering the definition of 'reasonably identifiable' and the factors outlined in Proposal 2.3. This reform would not impose an absolute or unworkably high standard on APP entities that use data for research or service delivery. Information could be considered anonymous provided that the risk of re-identification was extremely remote or hypothetical.' (Discussion paper, pages 30-31)

Research Australia is not opposed to the introduction of the concept of anonymisation but is wary about the implications this could have for research access to datasets, notwithstanding the assurance that the change will not impose an unworkably high standard on entities using data for research purposes.

There is emerging evidence that true anonymisation of data can rarely be achieved, or at least not without severely limiting the data made available. A risk-based approach to the consideration of whether data should be released is ultimately still likely to be necessary. Risk assessment requires the consideration to two factors: the likelihood of an event occurring; and the consequences of it occurring.

While an assessment of the likelihood that reidentification could occur is important, the consequences of that reidentification are what really matter to the individual. When considering whether and how data can be used for research purposes, the likely consequences of reidentification should be considered as well as the likelihood of reidentification occurring. For example, the reidentification of individuals from a publicly available dataset has much greater impact and is a greater risk to an individual's privacy than the same likelihood of reidentification in a dataset that is made available through a secure portal to a small group of researchers as part of a rigorous and legally enforceable research protocol.

Research Australia submits that any process to consider the risk of identification of individuals from a dataset provided for research must assess the whole risk profile of doing so (likelihood and consequence) and the measures that can be put in place to mitigate the impact of reidentification. Simply assessing the likelihood of reidentification without considering the measures to mitigate the consequences of such an event is insufficient.

The current NHMRC Guidelines for research refer to 'identifiable', 'de-identifiable' and 'potentially identifiable' information. If the concept of anonymisation is introduced, the Guidelines will need to be amended; more importantly consideration will have to be given to the circumstances in which this higher standard can, and cannot, be met, and the implications this may have for the conduct of research, and the balancing of the privacy of the individual with the public benefit of the research.

Research Australia is not suggesting this is necessarily incompatible with access to information for research purposes, but we are concerned about possible unintended consequences. It is a question which is not addressed in any detail in the Discussion Paper, so it is difficult to know if the implications for research of these proposed amendments have been given any serious consideration to date.

Research Australia submits the implications for research of the proposed change to anonymisation must be considered in parallel with the further development of amendments to the Act.

We further submit that an expert group should be formed specifically to work on the redevelopment of the NHMRC guidelines and in parallel with drafting of proposed amendments to the Act.

Research Australia submits that the use of information for research purposes should be explicitly included in the considerations of any regulatory impact statement.

Penalty for reidentification

The Discussion paper describes the history of the Privacy Amendment Re-identification Bill 2016, which lapsed in 2019. It notes that passage of the Bill a was not supported by the ALP and the Greens in the Senate, ‘on the basis it did not provide a proportionate, holistic response to de-identification Issues.’ (Discussion Paper, page 31)

The Discussion Paper proposes reintroducing the Bill with ‘appropriate amendments’ but does not discuss or describe what these amendments might be.

While unable to support the proposal at this stage for the reintroduction of the Bill without further detail of the ‘appropriate amendments’ **Research Australia submits the Government should actively consult with the research sector on the Privacy Amendment Re-identification Bill before its reintroduction.**

There should be further discussion about the circumstances in which reidentification would be an offence. **Research Australia submits it is important to consider circumstances in which reidentification might be inadvertent, and also to support the reporting of reidentification to the provider of the dataset as a means of improving the security and anonymisation of data.**

Harmonisation of privacy laws across jurisdictions

Research Australia shares many of the concerns expressed in the Discussion Paper about the inconsistencies in privacy laws across the Commonwealth, state and territory jurisdictions, and the complexity and confusion this creates. We are pleased to see that the Discussion paper identified health information as an area where there was a particular need to address these inconsistencies.

Australia’s health system is provided by Commonwealth, State and Territory governments and their agencies, the not-for-profit sector and the private sector. The fragmentation of health information and lack of interoperability is well known and has been well documented. It is also an area where economic and societal benefits will flow from greater harmonisation of legislative and regulatory requirements.²

² See, for example, Productivity Commission 2017, *Data Availability and Use*, Report No. 82, Canberra, Appendix E Case Study: Health Data

Research Australia was pleased to see the Commonwealth, State and Territory Governments reach a formal agreement ‘to share data across jurisdictions as a default position, where it can be done securely, safely, lawfully and ethically’ earlier this year.³

While recognising the agreement is limited to the exchange of data between governments, Research Australia believes the agreement reflects the emergence of a new and more positive environment within which to pursue harmonisation of privacy laws across jurisdictions.

Research Australia supports the proposal to establish a Commonwealth, state and territory working group to harmonise privacy laws.

Research Australia proposes that health information should be an area considered by the working group. While we recognise that it is one of the most complex areas, it is also the area where both the public interest and the potential benefit to individuals is greatest.⁴

³ <https://federation.gov.au/sites/default/files/about/agreements/iga-on-data-sharing-signed.pdf>

⁴ In 2015, the Productivity Commission produced a report which provides what remains a compelling case for the benefits of greater use of health information. Productivity Commission 2015, *Efficiency in Health*, Commission Research Paper, Canberra

Conclusion

Research Australia believes the better use of data is critical to both Australia's health and prosperity. 'Data and its transformative role in our health' is one of Research Australia's three core strategic priorities, reflecting just how important this area is to our sector.

The Privacy Act 1988, as one of the central pieces of legislation governing the collection, storage and use of personal information, is instrumental in shaping how, when and where health information can be used in Australia for research purposes, and this review of the Privacy Act is of critical importance to our members.

We are pleased to have had the opportunity to make this submission and welcome the opportunity to contribute further to the conduct of this Review.

RESEARCH AUSTRALIA LIMITED

384 Victoria Street, Darlinghurst NSW 2010

P +61 2 9295 8546 ABN 28 095 324 379

www.researchaustralia.org