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Response to the Report on the Review of the Privacy Act

The Attorney General's Department is undertaking a multi stage review of the Privacy Act 1988. On 16 February 2023 the Department published the Report of the Review of the Privacy Act and of the consultation undertaken in 2021 and 2022. The Report contains many proposals for amendment of the Act, a few of which have direct implications for the use of personal information in research, and consent to the use of information for research purposes.

Submissions were sought by electronic survey, which seeks feedback on only a subset of proposals. This paper covers the proposals relating to research, and Research Australia's responses to selected survey questions.

Personal Information, de-identification, and sensitive information

The Privacy Act regulates the collection, storage and use of personal information. Currently personal information is information 'about' a person. The Review proposes to change the definition to information that 'relates' to a person.

Sensitive information is a category of information that is subject to a higher level of regulation because of the potential for its disclosure or misuse to cause a higher degree of harm to an individual. Examples include personal health information. The Review proposes adding genomic information to the list of sensitive information.

This change is generally supported in the research community. Research Australia did not comment on this proposal.

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Research and Personal Information

When it comes to research, the core issues relating to the Privacy Act Review are:

- When is consent to the use of personal information for research required?
- What does the consent need to cover?
- When can personal information be used for research without consent under an exemption?
- When can personal information be used for research without consent and without needing an exemption?

Where the personal information is collected by the researcher from the individual, i.e. because the individual is participating in a clinical trial or a survey, obtaining consent to use the information for research is not normally a barrier, although the form of the consent, particularly in relation to other future research can be a problem.

The situation is different where a researcher is seeking to use personal information that has been collected and/or stored by another party for a different purpose, e.g. the provision of healthcare. Can this information be used if the individual has not consented to the use of their personal information for research? There are currently two provisions in the Privacy Act that permit some research with some personal information without the individual's consent. One relates to data held by Agencies (Government) and the other relates to data held by organisations (non government organisations covered by the Privacy Act).

The Review Report proposes several changes relating to research.

> ### Proposal 14.1
>
> Introduce a legislative provision that permits *broad consent* for the purposes of research:
>
> (a) Broad consent should be available for all research to which the research exceptions in the Act (and proposed by this chapter) will also apply.
>
> (b) Broad consent would be given for 'research areas' where it is not practicable to fully identify the purposes of collection, use or disclosure of personal or sensitive information at the point when consent is being obtained.

This proposal aims to address current issues about the nature and effectiveness of consent to the use of personal information for research purposes. This could apply where the data is collected by a researcher, but also where data is collected for a different primary purpose, e.g. healthcare, and the individual is asked to consent to the use of their personal information for research.

Proposal 14.1 was not included directly in the survey; Research Australia addressed this proposal in the other comments section at the end of the survey (see below).

There are also two proposals addressing situations where consent will not be required. Currently there is an exception from the requirement for consent that applies to medical research only (section 95 of the Privacy Act). Guidelines under this section are made by the NHMRC and relate to data held by an agency (i.e. Government Department or agency.)

There is also a provision under section 95A of the Privacy Act whereby the NHMRC has issued guidelines for medical research without consent using data held by an organisation (i.e. an entity covered by the Privacy Act such as a business).

Proposal 14.2

Consult further on broadening the scope of research permitted without consent for both agencies and organisations.

Proposal 14.3

Consult further on developing a single exception for research without consent and a single set of guidelines, including considering the most appropriate body to develop the guidelines.

Research Australia responses to the Consultation survey questions

Research Australia's survey responses addressing the above proposals are provided below.

Should the scope of research permitted without consent be broadened? If so, what should the scope be?

Research Australia supports broadening the scope of research permitted without consent. The current limitation prevents valuable research being undertaken, using, for example socio economic determinants of health such as education, income and housing status.

Should there be a single exception for research without consent for both agencies and organisations? If not, what should be the difference in scope for agencies and organisations?

Research Australia supports a single exception for research, applying to both agencies and organisations.

Which entity is the most appropriate body to develop guidelines to facilitate research without consent?

Research Australia supports further consultation on this question to help identify both the appropriate bodies to develop guidelines and provide ongoing, sector specific education and advice on interpretation.

The Review Paper recognises that deidentification is not static and that what is possible in terms of reidentification is changing rapidly. This changes both the nature of the guidance required and the frequency with which it needs to be reviewed and updated.

If you would like to provide general feedback on the Privacy Act Review Report please provide your response

Proposal 11.3 will 'expressly recognise the ability to withdraw consent, and to do so in a manner as easily as the provision of consent. The withdrawal of consent shall not affect the lawfulness of processing based on consent before its withdrawal.'

Research Australia agrees that withdrawal of consent needs to be as easy (if not easier) than providing consent. However, the exceptions must include where data have been analysed and published (there cannot be withdrawal after publication of results as this might lead to retraction of the article, and this would not be in the public interest). In addition, there are situations where the individual will be unable to withdraw consent (e.g. they have died) and their prior consent should remain as if they were alive.

It is unclear in the Review Report how this will be handled, and these factors should be explicit.

Proposal 14.1 will introduce a introduce a legislative provision that permits *broad consent* for the purposes of research. Research Australia supports this provision.

The provision must apply where the data is collected by a researcher, but also where data is collected for a different primary purpose, e.g. healthcare, and the individual is asked to consent to the use of their personal information for research. The consent must also be able to cover the re-use of data, linking their data to other sources and combining their data with other similar studies.