

ARDC submission on Data Sharing and Release Legislative Reforms Discussion Paper

10 October 2019

The Australian Research Data Commons (ARDC) has been established to address the National Research Infrastructure Roadmap priority of delivering a more integrated, coherent and reliable eResearch system for data-intensive, cross-disciplinary collaborative research. This research infrastructure is designed to strengthen Australia's position in the global research environment. The ARDC focuses on the development and use of integrated data-intensive infrastructure by promoting innovative and reliable approaches to the way Australian researchers and their collaborators create, find, use, share and store research data and tools.

ARDC has made several submissions to the data sharing and release initiative and has attended the roundtable sessions that have been held in Canberra, the last of which was 17 September. Overall, ARDC is more than comfortable with the aims and conduct of the data sharing initiative and the discussion paper.

Below the ARDC offers several suggestions to the overall initiative (which we understand comprises arrangements, the appointment of the National Data Commissioner, the forthcoming legislation), to the Discussion Paper as well as issues raised at the last roundtable.

1. Consent within the legislation

During a recent roundtable, the issue of consent was raised with some degree of concern in two senses: that the (in the sense that not achieving consent may potentially 'spoil' the intent of the legislation to some extent). A great deal of public sector data will not fall into the sensitive data category, where consent may be required. Sensitive data is generally construed as personal information, such as data that is legally privileged, personal financial or medical records, commercial-in-confidence, security classified, or sensitive environmental or cultural data.

Below are five considerations, all relating to sensitive data:

- (a) Sharing of sensitive personal information.

We would like to alert the Office of the National Data Commissioner to this ARDC guide, which was prepared in conjunction with several ethics committees and other experts: <https://www.ands.org.au/guides/sensitivedata>. Although prepared for the research community the *Publishing and sharing sensitive data* guide might also provide public servants with some working guidelines for what can and cannot be done with this class of data, with and without consent. Importantly, this guide references the key legislation which pertains to sensitive data.

(b) Sharing of sensitive data without specific consent.

Consent to share may not exist. Even where consent does exist, it may be for a limited use—which is commonly the case—or for more widespread sharing, which is probably much less common. Whether from a government department to another department or from a department to a researcher, this legislation (through the five safes model) has the potential to identify safe, legitimate, and valuable sharing of data which do not have specific consent.

The ARDC acknowledges the potentially large benefits to Australia of freeing up such data for research, government and other legitimate uses but suggests that the proposed legislation will need to address (specifically) the various types of sensitive information, as defined by the Privacy Act 1988 (Part II, Division I, Section 6) in order to achieve the best balance between benefit and potential risk or ‘conflict’ with the Act.

(c) Sharing of population data with implicit consent

There is also a perception that consent may be (or become) a potential issue for some kinds of ‘population’ data, such as the Census of Population and Housing or the PBS which are a normal part of the Australian landscape. Here, the ARDC does support the notion of a ‘waiver of consent’ which, in effect, has been the case historically and non-controversially for a long period of time. In many cases like this, there is no formal waiver; rather there is a shared understanding and trust between citizens and government agency, be it in relation to the Australian Taxation Office or the ABS, as examples. The ARDC does believe that whether consent exists formally or informally, especially if over long periods of time, the concept of a ‘waiver of consent’ is defensible and sensible in relation to population data.

d) Validity of opt-out models of consent

System wide registries, such as clinical quality registries, provide important functions for system improvement, such as benchmarking of clinical good practice across the health system. For some examples see:

https://www.monash.edu/data/assets/pdf_file/0005/1219379/Monash_Clinical-Registers.pdf.

The statistical integrity and community trust of these registries relies on their system-wide default coverage which is often achieved by an opt-out consent model. In the clinical quality registries example, this opt-out approach has historically achieved a participation of greater than 95% . The ONDC guidance around consent should take into account the significant health, well-being, and economic benefits that are currently enabled by the opt-out model in certain justified circumstances; such benefits will be endangered by excluding legitimate opt-out and moving towards an absolute, specific, and explicit consent approach.

The example given here of hospital records probably falls out of direct scope for this Commonwealth legislation, however any signals from the Commonwealth of a change in validity of the opt-out consent model would have serious knock-on effects for such registries.

These registries are often significant public-private-research sector collaborations.

(d) Aboriginal and Torres Strait Islander (data and information)

Data involving Aboriginal and Torres Strait Islander people should be considered as potentially (culturally) sensitive data and referred to the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS).

2. Evidence for the benefits to government of research

In the recent roundtable, and also in the discussion paper, participants were apprised of the view that some people doubt whether (the outputs of) research was of real benefit to Government; the context here is that researchers are one of the groups that are targeted as legitimate users of data freed up by the proposed legislation.

Fortunately, there is ample data, research and evidence to suggest a very positive link between research and value to government and the wider community.

<https://apo.org.au/node/31390> (Australia)

<https://impact.ref.ac.uk/casestudies/#> (International)

<https://www.ands.org.au/working-with-data/articulating-the-value-of-open-data/open-research-data-report> (Economic value of research data to Australia)

<https://www.ands.org.au/working-with-data/articulating-the-value-of-open-data/costs-and-benefits-of-data-provision> (Economic value of public sector data to Australia)

The ARDC has a draft report on data impact, relating to the EU, which demonstrates a direct and facultative link between data and wider community benefits. We will share this with the ONDC as soon as we are able.

3. Scope of the Data Sharing and Release Initiative¹

The discussion paper includes the following definitions (quotes):

- *Public sector data is information collected or generated by Commonwealth entities (such as departments) and Commonwealth companies, or through research programs funded by the Australian government.*
- *Public sector data is data held by the Australian government as it fulfils its various functions. Government agencies collect, hold and use data on topics as diverse as*

¹ The initiative comprises the appointment of the National Data Commissioner, legislation and other associated arrangements

weather patterns, who is coming and going from Australia, and administrative data about access to government services by both businesses and individuals.

The ARDC looks forward (post legislation) to continued collaboration with the ONDC on its broader data sharing and release agenda to ensure a harmonious national policy framework across research and public sector. It should be noted that the current data policies in the sector² are very consistent with the data sharing and release principles.

4. Existing Research Sector Safeguards

Where researchers are making use of the new legislation under the proposed research purpose, ARDC recommends that ONDC takes into account existing research sector safeguards such as ethics committees, grant review panels, and codes of conduct of research. Proliferation of red-tape through new ONDC tests for valid research projects would be counter to the spirit of the initiative which is to streamline access to Commonwealth data.

5. How important is copyright to the Data Sharing and Release Initiative?

There seems to be quite a widespread belief that data cannot contain copyright and, as such, cannot be licensed. Many people also believe that it is not necessary to license data for others to use it. Neither of these statements are true; some data definitely will attract copyright protection and can (and should) be licensed; furthermore, not having a license is the same as saying “all rights reserved” in which case no-one can use it.

The ARDC commissioned a guide to deal with copyright and licensing, which is here: <https://www.ands.org.au/guides/research-data-rights-management>

The contact for this submission is Dr Adrian Burton, Director, Data, Policy and Services

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² <https://www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018> (note supporting data guide in links) <https://www.arc.gov.au/policies-strategies/policy/arc-open-access-policy-version-20171> <https://www.nhmrc.gov.au/about-us/resources/open-access-policy>