SUBMISSION TO THE DATA SHARING AND RELEASE LEGISLATIVE REFORMS DISCUSSION PAPER

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Submission to the Data Sharing and Release Legislative Reforms Discussion Paper

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Thank you for the opportunity to make submissions to this inquiry. We do so in our capacity as experts in technology law and as members of the Allens Hub for Technology, Law and Innovation at UNSW Law rather than in an institutional capacity. We would like to commend the substantial consideration which has been given to the community and stakeholders by conducting an extended consultation process. Benefits of the extended engagement are reflected in policy adjustments and the promotion of the public conversation around data-use. We note that we have previously submitted a response to the *Issues Paper on Data Sharing and Release* legislation and attended consultation sessions. We are grateful for the opportunity to continue participating in the consultation process.

In relation to the Discussion Paper, we make the following points:

1. The need to develop a consistent legal framework and consistent language around data governance;
2. The concept of consent has limited practical utility regarding government re-use of its data;
3. Concerns about non-consensual use of data for commercial purposes could be addressed by requiring a research ethics process such as that operating in universities and hospitals;
4. Where possible individuals should be notified that their data has been shared or released;
5. The need for consistency surrounding the types of data specifically excluded;
6. Data-sharing for public benefit should incorporate express protections for human rights, for instance by:
    a. refining the purposes test;
    b. expressly preventing use for non-compliance enforcement;
    c. enabling individuals to opt-in to "tell us once".

The need to develop consistent legal framework and language

As we previously noted in our response to the *Issues Paper on Data Sharing and Release*, the current law around government information-sharing is unnecessarily complex. There is a patchwork of laws dealing with the sharing of government information which results in confusion and reluctance within government agencies to use existing data-sharing and release mechanisms. Efforts to develop context-specific laws, such as consumer data right, or for automated vehicles, or for data sharing for research purposes, despite the potential merits of each, contributes to this complexity.

The Discussion Paper acknowledges the need for clarity within this space, expressing a desire to simplify information sharing processes and shift the Australian public service culture towards responsible sharing. The relationship between the Data Sharing and Release legislation and other existing data protection provisions (such as the *Privacy Act 1988* (Cth) and secrecy provisions) has been clarified. However, the parallel operation of these reforms alongside existing provisions has the potential to add complexity, particularly where it introduces new terminology (such as "sharing" rather than "disclosure", "data" rather than "information" and, potentially, new terminology linking entities and data).[1]

Consent and government use

The position on consent has been nuanced in the Discussion Paper, with the acknowledgment that societal outcomes of fair and unbiased government policy, research and programs can outweigh the benefits of consent. We agree that consent is a complex issue, noting that citizen consent cannot be essential for most uses of data collected by governments about citizens anyway, as dealings with government services are not necessarily by choice.[2] Additionally, consent is already not required for a range of data-sharing activities conducted by government agencies including the Australian Institute of Health and Welfare for medical research and the federal government's Multi-Agency Data Integration Project.[3] Consent is not useful when dealing with government as most people do not consent to being citizens. Focus should be placed on the promotion of responsible practices regardless of consent.

Consent and commercial use

The Discussion Paper considers the question of whether data should be shared, without consent, with commercial entities that claim to have a public purpose in mind. Realistically, this would fall into the purpose category of "research and development". Following on from discussions in the Consultation on 23 September, there are challenges in determining eligibility for the scheme by reference to sector. For example, companies often partner with universities in

[1] The vast array of existing terminology is discussed in the attached draft paper, which we ask to be kept confidential.
[2] Peter Leonard, 'The long and winding road to fair and responsible Government data sharing in Australia' (2019) *Privacy Law Bulletin* (forthcoming).
[3] Ibid.

collaborative research projects. However, in the context of research, an important distinction is whether or not research is reviewed by a research ethics committee (which are the rule in universities, hospitals and some government contexts). Such committees routinely decide whether consent is required and the form that any such consent should take. This analysis is deeply contextual depending on the nature and importance of the research, the practical challenges of obtaining consent, and whether the research question can be answered if consent is a pre-requisite. For example, deception studies in psychology can be approved without requiring participant consent. The Discussion Paper acknowledges that the societal benefits of research may in some circumstances outweigh the benefits of consent. For research conducted through research organisations with an ethics committee review process, the issue of consent can be delegated to those committees.

In contrast, commercial bodies rarely seek ethics approval for research. The rules in the Privacy Act thus provide a useful framework for specifying the circumstances in which consent need not be sought. Where commercial entities partner with universities, hospitals or government in their research, the research projects will generally fall under the jurisdiction of that partner's ethics process. There is no reason to exclude commercial entities from the data sharing scheme in these circumstances.

We thus suggest that "research and development" as a purpose be defined as "research and development that has been approved by an institutional ethics review process". It is possible that commercial research and development companies will create a research ethics review process that mirrors the rigour and independence of the ethics processes of universities and hospitals. There is thus no need to exclude based on sector alone, but definitions will be needed to ensure that the process is sufficient.

Notification

Recognising the rights and agency of data subjects suggests that, wherever possible, individuals should be notified that their data (1) could and/or (2) has been shared under the legislation. Notification can also assist enforcement measures by guiding individuals who wish to investigate whether their data has been unlawfully shared.[4] As a second-best solution, individuals could be given a right to ask how their data has been shared. In the case of research, the form of such notice or the manner of response to information requests could be a question for ethics review, meaning that context can be taken into account. At a minimum, existing government privacy policies will need to be updated in order to explain the new scheme, so that individuals are aware that their data could be shared under the legislation.

[4] In accordance with the right to an effective remedy under Article 2.3 of the *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976).

Consistency for specifically excluded data

Information collected or held by the national intelligence community and information provided under the 'My Health Record' scheme are specifically excluded in the Discussion Paper. We commend the exclusion of data-sharing for compliance and law enforcement purposes, however this must be made clear and explicit in the legislation. Presumably, health information outside the 'My Health Record' scheme is also excluded as it is not held by the Commonwealth government. Nevertheless, a broader category of exclusion would ensure that, if the legislation is mirrored by states and territories, those who opted out of the My Health Record scheme are similarly protected. Otherwise there is a risk that citizens will be incentivised to have a 'My Health Record' as a by-product of inconsistent data exclusion.

Protection of human rights when sharing data for 'public benefit'

Data-sharing for the public benefit, including sharing to improve government policy and programs, research and development, and government service delivery should incorporate express protections for human rights. The use of a data map providing support for drought affected individuals has clear benefits for those individuals suffering from adverse weather events. However, the current 'purpose test' does not preclude programs, research or delivery which may adversely affect the human rights of the targeted cohort or individuals. Consideration should be given as to whether the purpose test would permit the use of data sharing for programs such as cashless welfare or mandatory drug testing where "services" can have a perceived negative impact or can adversely impact on human rights. One option would be to refine the purpose test to limit it to situations where individuals are benefitted and their human rights are protected or, at minimum require that interference with human rights are justifiably proportionate.

It is appreciated that data duplication when the individual deals with various government departments and organisations, can be a frustrating and tedious part of seeking government assistance or services. However, the individual does have a right to not inform some government departments about their circumstances, for example where they do not wish to receive services to which they are entitled for personal reasons. To protect such individuals while benefiting the majority who may find "tell us once" convenient, a check box can be introduced that allows individuals to opt in to "tell us once".