

# DATA AVAILABILITY AND TRANSPARENCY BILL 2020

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Response to the Exposure Draft

Population Health Research Network

6 November 2020



# 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.

## 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



# PHRN RESPONSE TO THE EXPOSURE DRAFT

## 1. Scope of the Data Availability and Transparency Bill 2020

In our response to the Data Sharing and Release Legislative Reforms Discussion Paper 2019 we requested additional clarification about whether state and territory government data e.g. hospital admissions data, held by a Commonwealth Government agency e.g. AIHW, would fall under the new legislation or whether it would remain under the auspices of relevant state government legislation and any data sharing agreement between the state and the Commonwealth.

The Exposure Draft, clause 11(2), is clear that state and territory government data held by a Commonwealth body could only be shared under this legislation if there was a data sharing agreement that declared the Commonwealth body to be the data custodian. However, clause 13 of the Explanatory Memorandum states:

*“Where the above requirements are met the Bill provides a limited statutory authority to share public sector data, despite other Commonwealth, State and Territory laws that prevent sharing. This override of non-disclosure laws is ‘limited’ because it occurs only when the Bill’s requirements are met, and only to the extent necessary to facilitate sharing.”*

What are the circumstance under which the Data Availability and Transparency Bill would override existing State and Territory laws?

## 2. Will the Data Availability and Transparency Bill 2020 Streamline Access to Commonwealth Data?

In the case of health and human services research using Commonwealth data the Data Availability and Transparency Bill 2020 seems unlikely to achieve more streamlined and safer sharing. As mentioned in our responses to the 2018 and 2019 discussion papers, in most cases there is already clear legislative authority to share this data for research. The most significant impact will be to embed the existing practices in legislation.

Whilst there will likely be benefits in providing legal authority where it is currently prohibited we remain concerned as articulated in our 2018 submission in circumstances where there is existing legal authority.

*“This approach runs the risk of increasing rather than simplifying the legislative complexity by just adding another piece of legislation for data custodians to consider. If data custodians are able to choose which legislation they wish to apply then there is a risk that they may treat applicants for data inconsistently, that is, they may choose to apply the more permissive framework for some applicants and the more restrictive framework for others. This has the potential to lead to actual or perceived bias in decision-making, which are both inconsistent with the principles of good administrative decision-making. Bias, or the perception of bias, will undermine trust among applicants and the community.”*

Without a significant increase in funding for data custodians and accredited data service providers it seems unlikely they will be able to respond in a timely way to the anticipated increase in requests for data and also apply the requirements of the new legislation.

## 3. Public Interest

There was a strong emphasis on the concept of public interest in data sharing in the previous two discussion papers. The PHRN is surprised that this concept is significantly diluted in the Exposure Draft given the importance to the community that data sharing is in the public interest and the importance of weighing the public interest in privacy versus the public interest in data being shared or released. The Exposure Draft does not require any independent assessment of public interest before data is shared. The only requirement is that *“a description of how the public interest is served by the*

*sharing is to be set out in the data sharing agreement*". The data custodian and other entity entering into the data sharing agreement will need substantial support and guidance to be able to assess and describe the public interest in the data sharing arrangement.

It may be assumed that existing ethics processes will provide an independent assessment public interest given the requirement in the Exposure Draft that *"any applicable processes relating to ethics are observed"*. However, for the permitted purposes, government service delivery and informing government policy and programs, there are unlikely to be any formal ethics processes that must be observed.

For human research projects, the research should be conducted in accordance with the National Statement on Ethical Conduct in Human Research. It should be noted that changes to the National Statement are currently proposed which if accepted would mean that research of minimal risk would not be reviewed by an HREC and may be completely exempt from review. It is also proposed that any research conducted on behalf of a government agency involving data is exempt from ethics review.

These proposed changes if accepted will likely create further confusion about whether projects involving a waiver of consent require HREC review.

#### **4. Data Sharing for Commercial Purposes**

Private industry is an integral part of the Australian health system and has an important role in health care delivery as well as the development of new therapeutic interventions. Therefore the PHRN is pleased that access to data for private industry has not been precluded in the Exposure Draft. However, any data sharing with private industry should be done for purposes and in ways that are acceptable to the Australian community.

We recently commissioned The Australian Centre for Health Engagement Evidence and Values at the University of Wollongong to examine community attitudes towards governments sharing linked administrative health data sets with private companies for research and development of treatments for disease and disability.<sup>1</sup> Subsequently further research was conducted on this topic using citizens' juries. This research has demonstrated community support for some data sharing with private industry subject to a number of conditions including:

- Who can access
- What form of data can be shared
- Oversight by independent body
- Purpose of sharing
- Protections, penalties and cost
- How to inform public
- Consent

The Exposure Draft covers most of these conditions in some way. However, despite the proposed role of the Office of the National Data Commissioner it does not include the level of independent oversight envisaged by the community members who contributed to this research. In addition the comments above about public interest are even more important in regards to data sharing with private industry. The legal obligations of private companies to their shareholders must take precedent over the public interest and therefore whether data sharing with private industry is in the public interest will require careful consideration.

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<sup>1</sup> <https://www.phrn.org.au/media/81832/report-summary.pdf>

## 5. Accreditation

The PHRN is supportive of an accreditation system to assist in meeting the transparency requirements of the new legislation. Accreditation of Accredited Data Service Providers who are offering specialist data services is strongly supported. Further consideration of the accreditation framework for users at the organisational and individual levels is required to ensure that accreditation is both meaningful and not unduly burdensome. In particular it would be worthwhile considering case studies of how accreditation would work in practice. For example, it appears that only accredited users can enter into data sharing agreements. If this is the case, a researcher from an unaccredited university would not be allowed to access data through an Accredited Data Service Provider even though the risks of such an arrangement would appear to be extremely low.