

DATA AVAILABILITY AND TRANSPARENCY BILL 2021

Submission to the Senate Finance and Public Administration
Legislation Committee

Population Health Research Network

12 March 2021



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

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Introduction

The PHRN welcomes the opportunity to make this submission to the Senate Finance and Public Administration Legislation Committee.

The PHRN supports the Data Availability and Transparency Bill (the Bill) that is currently before the Senate. We participated in the Productivity Commission Inquiry into Data Availability and Use in 2016 and 2017 and supported many of the recommendations to improve access to data for research. We participated in the extensive three-year consultation process conducted by the taskforce established by the Department of Prime Minister and Cabinet and led by the Interim National Data Commissioner on the Bill and made three written submissions during this process. We believe the Bill and the framework for data availability it establishes are an appropriate and effective way to enable the Australian community to reap the benefits of research with minimal privacy risks.

Submission

The PHRN supports the passage of the Bill by the Senate. The PHRN has more than 10 years' experience in sharing sensitive personal information for internationally significant research in ways that minimise risks to individual privacy but enable important research that improves the health and wellbeing of Australians. We experience daily the challenges of balancing risks to individual privacy with the individual and community benefits that result from high quality research.

We note the Scrutiny of Bills Committee report published on 29 January 2021 and the concerns raised, many of which were raised during the consultation process.

As raised in our previous submissions, the Data Availability and Transparency Bill, will embed existing good data sharing practices into legislation. We believe that the Bill will not erode existing privacy protections but will clarify and standardise data sharing requirements for data custodians. We believe that most of the concerns raised by the Scrutiny of Bills Committee regarding risks to individual privacy are adequately covered by the Bill.

The PHRN does share some concerns about the evaluation of public interest with the Scrutiny of Bills Committee. There was a strong emphasis on the concept of public interest in data sharing during the consultation process. This concept is significantly diluted in the Data Availability and Transparency Bill. It is very important to the community that data sharing is in the public interest and that the public interest in privacy versus the public interest in data being shared or released is carefully assessed. The Bill 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. This will be particularly important when considering sharing data with private companies. 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.

Conclusion

Australia has a long history of internationally significant research conducted with linked administrative data. This history has been underpinned by good data sharing practices that minimise the risks to individual privacy. However, the variation in legislation covering different data collections and jurisdictions has made it challenging for researchers to easily access data for valuable research that results in improved health and wellbeing as well as economic benefits.

The Bill was developed with extensive consultation with a wide range of stakeholders. The PHRN believes that overall it delivers an effective balance between minimising individual privacy risks and maximising the benefits from the sharing of data. The PHRN supports the passage of the Bill to the Senate.

The PHRN is pleased to have had the opportunity to make this submission and is willing to provide further information if that would assist the Committee in its deliberations.