

# Privacy and Responsible Information Sharing for the Western Australian Public Sector Discussion Paper

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## Response to the Discussion Paper

Population Health Research Network

1 November 2019



# 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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# PHRN RESPONSE TO THE DISCUSSION PAPER

## Introduction

It is in the public interest for personal information collected by WA government agencies to be shared and linked for research and development for the public benefit.

There is an urgent need for a clearly articulated privacy regime in WA. The lack of privacy legislation has been cited as a reason why Australian government agencies in other jurisdictions will not share data with WA researchers and data linkage units. Without privacy legislation or an easily demonstrable equivalent privacy regime, WA organisations cannot be accredited as Commonwealth Integrating Authorities and would be unlikely to be accredited as Accredited Data Service Providers under the proposed new Commonwealth Data Sharing and Release legislation. This will limit the research that researchers in WA can do at a national level and the ability of WA to contribute to nationally significant research. There is a risk that if data from WA is not able to be included in national research then any WA specific anomalies or significant differences will not be identified and could impact the research outcomes to the detriment of the people of WA.

## PHRN Recommendations

The PHRN strongly supports the implementation of a WA Privacy regime, including data sharing legislation. To meet the requirements of the WA and Australian research community, the new legislation needs to ensure that:

1. **The WA Privacy regime is in a form that will be recognised by other Australian jurisdictions** and will not create a barrier for WA data to be shared with other Australian jurisdictions. It also needs to allow the sharing of data from other Australian jurisdictions with researchers in WA. At a minimum it should be in a form equivalent to existing privacy legislation in other Australian jurisdictions.

We note the WA Government's desire to lead the country and provide a new Privacy regime that is forward thinking and aligns more closely with modern privacy principles reflected in European privacy models. PHRN would support legislation that is forward thinking and will enable data sharing beyond Australia, provided that it did not cause undue delay in implementation of the new regime (see Section 5 below for further comment on timing).

2. **Any identifiable information in a data record held by WA government agencies is able to be shared with the WA Data Linkage System as well as with equivalent data linkage units in other Australian jurisdictions.** This will maintain the WA Data Linkage System and enable cross-jurisdictional linkage.

Linking data from multiple sources both within WA and across jurisdictions about the same individual is essential for a wide range of important research. High quality linkage requires the use of identifiable data such as name, address, sex and date of birth. When this data is supplied to a specialist data linkage unit, such as the WA Data Linkage Branch, it is not sensitive as it is separated from the other information in the record e.g. diagnosis which may be sensitive. The identifying data in each record for one individual across the various data sources is "matched" and a new identifier is created, allowing data from multiple sources to

be linked together without the whole record being provided to the Data Linkage Unit. As such, the data used for linkage represents an extremely low risk of harm to the individuals whose data is linked.

Any restriction in the WA Privacy regime on providing personal identifiers to any Australian data linkage unit will be a severe hindrance to high quality linkage. If the new Privacy regime prohibits the provision of personal identifiers, then the PHRN supports the enactment of a supporting data sharing exemption (or separate legislation) which would enable a specific exemption for research purposes through an approved Australian Data Linkage Unit.

It is noted that the WA Data Linkage Branch has linked a wide range of health and human services data over more than 20 years and there is legislative authority to share data for research for many WA data collections. Many government departments that collect data have provision in either the legislation or their supporting regulations to allow the release of personal data for research purposes in WA. For example, the *Health Services Act 2016 (WA)* section 216 (d) specifically authorises the CEO of the Department of Health to disclose health information collected by the Department for the purposes of “health related research”. Another example is *Health (Western Australian Cancer Register) Regulations 2011 (WA)* where regulation 12(1) (a) allows the Chief Health Officer to “authorise the disclosure of information on the register for the purpose of research”. An overarching legislative right to access personal data for research purposes would provide clarity to those working outside of the specific WA departments, as to the right to release and the right to access personal data rather than the current piecemeal approach.

3. **The application and review processes required for researchers across Australia to access data for research are transparent and not disproportionately onerous compared to the level of risk of the proposed data use.** The processes for applying for data across the country are currently unduly burdensome. The PHRN is actively seeking to address this issue via the provision of project funding to Australian data linkage units if they seek to implement streamlined processes and shorten approval timeframes. We recommend that the process for application under the new WA Privacy regime should align with the aim to streamline access to data for research and not create an unnecessarily onerous and time consuming burden. To this end we recommend that the legislation and/or supporting regulations mandate a transparent process supported by indicative timelines with senior executive oversight and standardisation across government agencies.
4. **The WA Privacy regime should include a transparent process for appeal if access to data is denied and a clear mechanism for complaint resolution.**
5. **The Privacy regime is enacted as soon as possible.** As discussed above, WA is regularly not being included in national research, due to the lack of a comprehensive and clearly articulated Privacy regime. This results in WA researchers and the WA Data Linkage System not being able to access data from other Australian jurisdictions, which severely limits research at a national level in WA. There is also a risk that organisations that are sources of important data for research in WA will not be able to be accredited under the proposed Commonwealth Data Sharing and Release legislation. It is the PHRN’s position that whilst we are supportive of a new and forward thinking model, the new Privacy regime should not be unduly delayed while determining the optimum model.