



PRIVACY AND RESPONSIBLE INFORMATION SHARING FOR THE WESTERN AUSTRALIAN PUBLIC SECTOR

[Response to Discussion paper](#)

As Western Australia's largest Medical Research Institute, the Telethon Kids Institute welcomes the introduction of Privacy and Responsible Information Sharing Legislation in Western Australia. State privacy legislation is essential to support and enable current and future health and social research in WA. The lack of such legislation has long been a barrier for the sharing of important information locally, nationally, and internationally. This has had significant impacts upon the quality and quantity of research that can be conducted in Western Australia.

Please see below our response to the Discussion paper.

[What issues should be considered when developing privacy and information sharing legislation for Western Australia?](#)

Of most concern to us as researchers is that the proposed legislation aligns with, and is acceptable to, other jurisdictions, both Nationally and Internationally. In order for Privacy and Responsible Information Sharing Legislation to be an enabler, rather than a barrier, it is imperative that we ensure there is nothing in the legislation which will prevent the sharing of data and information between WA and other jurisdictions. We also feel that this presents an important opportunity for WA to future proof its legislation and ensure that it is aligned with the European Union General Data Protection Regulations (GDPR).

In addition, we feel it is important to ensure that any new data sharing processes that arise from the proposed legislation are both streamlined, and interoperable with other jurisdictions.

The proposed legislation should ensure that any identifiable/personal information held and/or collected by the WA Government can be shared in a way that enables best practice data linkage for research and evaluation. This includes linkage within the State, Nationally and Internationally.

We also feel that it is important to focus on the use of public sector data for public benefit and highlight this in the legislation in order to gain the trust of the public.

The legislation must provide a clear framework for interpretation and implementation to ensure decisions about data sharing are made in an effective and timely manner at an organisational level, rather than by individuals within a department exercising their own interpretation of the policy.

We feel that the Five Safes is an appropriate way to safeguard the use of personal information. We also feel that it is important for the legislation to acknowledge and take into consideration Aboriginal data sovereignty. This will require an understanding of emerging state, national, and international discussions around Indigenous data sovereignty and data governance, and associated principles, protocols and processes.

What should the role of a Privacy Commissioner and Chief Data Officer be?

The Privacy Commissioner should have an overarching monitoring and governance role and should be independent of any government agency; the legislation will need to reflect this. In order to gain public trust, it is important that the Privacy Commissioner is given independent powers to investigate accusations of data and privacy breaches.

The role of the Chief Data Officer should be operational. The Chief Data Officer could be involved in activities highlighting the importance of data sharing and offer training to government employees. They should also be involved in determining data classification processes, and deal with complaints regarding decisions to not share data. They should also be involved in discussion and decision making in regard to access to high value datasets and their data quality improvement.

To ensure that the aspirations and development agendas of Aboriginal people are represented, it is important that both roles consider issues around Indigenous data sovereignty and facilitate the participation of Aboriginal people in data governance activities across sectors and regions.

How should breaches of privacy be managed, and what action should be taken in response to a breach?

There should be a clear process to follow for accusations of privacy breaches. These should be overseen by the Privacy Commissioner. The action taken in response to a breach should be dependant upon the 'type' and 'intent' of the breach.

When should government agencies be allowed to share personal information? Are there any circumstances in which it would not be appropriate to do so?

With respect to sharing personal information for research and evaluation, we believe government agencies should be allowed to share personal information when a recognised ethics review panel has deemed the request ethical, and all safeguards have been put in place to ensure no harm will come from the sharing of that information. If the benefit to the WA community outweighs any potential risk, then we believe information should be shared.

Should the WA Government facilitate sharing of information outside the WA public sector? What should be considered when making a decision to share outside the WA public sector?

As noted above, we believe it is imperative that the WA government facilitate the sharing of information outside the public sector for research and evaluation that has clear public benefit. It is important to note that the data collected by the WA Government belong to the WA Public. The WA Government has an obligation to use that information appropriately and for the benefit of the people of WA.

What should the WA Government be doing to support successful implementation of privacy and information sharing?

There needs to be adequate resourcing within government to ensure data can be shared and linked, as a matter of course. Continuing underinvestment in WA's linked data sector limits the enormous potential of routinely collected administrative data to inform government policy and programs across all human services portfolios. Ideally, a comprehensive system supporting data integration, data governance, data access (for approved projects and personnel) and data security would be standard government infrastructure. These essential tasks could be undertaken by an existing facility (i.e. the WA Data Linkage Branch, pending additional resourcing), but the creation of a new legal entity designed specifically for the role, and independent of all data custodian agencies, would represent an advance and place WA at the forefront of these activities. The need for a whole of government data sharing strategy and framework is essential to successfully support the implementation of privacy and information sharing across government.

In addition, there needs to be public education around data sharing, the benefits that come from it, and the safeguards that are put in place to ensure that the public can have trust in the processes.

There is a need for a change in culture in the Public Sector with respect to data sharing. Traditionally, many data custodians have been risk averse when sharing data. The legislation should ensure that data sharing is promoted as a standard operating process. The role of data custodians should change so that custodians no longer make decisions regarding the release of data for research or evaluation, but they assess data requests for "fitness for purpose".

Need to expedite the legislation

As a final, yet important point, we feel that it is imperative that this legislation is passed in the current term of government. WA has already suffered from significant delays in the implementation of privacy and data sharing legislation, any further delays will have even greater impacts upon WA researchers, and the WA community who benefit from the research.

The lack of privacy legislation has impeded WA's ability to receive and link Commonwealth data for research purposes. Ensuring new WA Privacy and Responsible Information Sharing Legislation is drafted in a way that aligns with similar new Commonwealth legislation being developed by the Office of the National Data Commissioner will help WA to deliver more effective use of all Australian administrative data resources for the benefit of the WA community.