

Trust issues prevent sharing of vital health and welfare data in Australia, finds study

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A lack of trust between institutions in Australia is a bigger hurdle to the easy sharing of health and social welfare data than perceived state legislation obstacles—which researchers say largely don't have a detrimental effect in Australia.

The sharing of health and social welfare data between institutions in different states of Australia could result in greater efficiencies of service delivery, yet barriers to inter-institutional and jurisdictional sharing of health and social welfare data are frequently reported.

A scoping review by researchers from Flinders University, Queensland University of Technology and University of Queensland analyzed published literature from Australia to see what regulations were used to justify not sharing data, and found that most regulations in Australia governing health data are relatively consistent.

Regulation, ranging from legislation to institutional policies and guidelines, is frequently cited as a barrier to [data sharing](#)—but the scoping review found that with the exceptions of South Australia and Western Australia, there is relative consistency between privacy regulation in different Australian jurisdictions.

The article, "Does Legislation Impede Data Sharing in Australia Across Institutions and Jurisdictions? A Scoping Review," has been [published](#) in the *Journal of Medical Systems*.

"This could demonstrate that the impact of privacy regulations to limit data sharing is due to the perceived rather than actual impact of such regulation," says lead author of the paper, Dr. James Scheibner, a data

privacy and health law experts from Flinders University's College of Business, Government and Law.

The absence of a uniform procedure for ethics approval between different states was also cited as a barrier to inter-jurisdictional health and social welfare data sharing.

However, regulations are not the only impediment to data sharing. Several of the studies examined by the researchers highlighted a lack of trust among various stakeholders in data sharing initiatives, including public and [health](#) care practitioners.

"This lack of trust can lead to stakeholders refusing to contribute to data sharing initiatives, thereby undermining the consistency of such data," says Dr. Scheibner.

Incomplete datasets were also a barrier to sharing, which may be driven by people unwilling to opt their data into such collections.

Considering these challenges, the researchers say that policymakers should focus on coupling initiatives to increase data availability with stakeholder consultation. This consultation would likely ensure the benefits of data sharing were more widely understood, and therefore help to build [public trust](#).

More information: James Scheibner et al, Does Legislation Impede Data Sharing in Australia Across Institutions and Jurisdictions? A Scoping Review, *Journal of Medical Systems* (2023). [DOI: 10.1007/s10916-023-02009-z](https://doi.org/10.1007/s10916-023-02009-z)

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