



Contribution ID: 117

Type: **Presentation**

Connecting researchers to the Australian data linkage landscape through institutional investment and communities of practice

Wednesday 15 October 2025 15:06 (11 minutes)

Situation

Recent technological progress has significantly enhanced our capacity to link person-level data across diverse sectors for research in Australia. Key advancements include: legislation to facilitate data access and availability, streamlined governance processes, enriched metadata, more efficient data linkage, and enhanced statistical methods and training. Collectively these advancements have created significant opportunities to maximise data sharing and expand the utilisation of existing research data across multiple domains but not without creating additional complexities for researchers.

Task

Monash University has long been recognised for its leadership in Health, Social, Epidemiological, and Translational research. Monash supports over 43 registries, 700 clinical trials, and 47 cohort studies, each leveraging complex, multimodal, large, and often sensitive datasets with many linked to administrative health datasets that exist at multiple levels of government in Australia. However, many of these research activities have been occurring in isolation. In response to the need for internal capacity building and increased potential to leverage national and global advancements in population data linkage, Monash University has significantly invested in data infrastructure, networks and highly skilled people to support best practice in data linkage and population research.

Action

In 2019, Monash University established M-Link - a community of practice to advance data linkage capabilities across all schools and faculties. An initial multidisciplinary working group was established –covering expertise in data management, data governance, privacy, data engineering, statistics and epidemiology. The overarching objective of the group was to develop a comprehensive roadmap for expansion to a university-wide community of practice. In parallel, Monash invested in infrastructure support through the establishment of a Monash hosted Trusted Research Environment.

As these activities progressed it became increasingly clear that the many challenges could not be addressed solely at an institutional level and that collaborative approaches across institutions and with government funded bodies were required. Advocacy for data linkage included submissions to government agencies on availability of their data and culminated in the establishment in 2023 of a Monash DATA (Data Availability and Transparency Act) scheme accreditation working group to provide collective leadership for Monash's accreditation as a data user

for Australian Government data, resulting in Monash being one of the first institutions to be accredited under the scheme. In addition, events have been organised in response to member surveys every six months with leading researchers and data custodians to share knowledge and increase exposure of data linkage capacity at the University.

Results

Over the past six years, M-Link has successfully cultivated a thriving community of practice at the institutional level, growing from a working group of 10 volunteers to a community of over 130 researchers. Activities undertaken by Monash at the institutional and national level supported Monash to be one of the first academic institutions to become an accredited data user under the DATA scheme.

The expansion of M-Link into the national landscape led to 143 researchers from multiple institutions registering for a national co-hosted event. Activities revealed that while government data custodians, infrastructure providers, and researchers acknowledged the value of advancements in linkage technology and data availabil-

ity, these came with new challenges such as navigating multiple TREs, rising data provision costs and the enduring issue of timeliness.

The workshop highlighted that by fostering knowledge exchange and promoting best practices in data linkage across Australia, initiatives like M-Link serve as crucial connectors between researchers and government entities providing valuable insights into the research community's perspectives on service delivery models. This has positioned M-Link to drive the conversation within the University to promote collaborative approaches to extend data use and fully leverage research data's value.

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Session Classification: Presentations Session 8: Policy and Practice of Data in Research; Data, Society, Ethics and Politics

Track Classification: SciDataCon2025 Specific Themes: Infrastructures to Support Data-Intensive Research - Local to Global