

## IMPROVING ACCESSIBILITY AND LINKAGE OF DATA TO ACHIEVE BETTER HEALTH OUTCOMES FOR ALL AUSTRALIANS

### SUMMARY

Patient and public health records are an extremely valuable resource that have the potential to drive improvements in medicine and healthcare through research and quality improvement programs. To reap these benefits, Australia – led by action from Federal and State/Territory Health Ministers – needs to build on existing efforts to enable efficient, rigorous, safe and secure use of data for research, while protecting the rights and interests of individuals.

### BACKGROUND

Most Australians support – and indeed expect – their health data to be used in ways that improve treatment and care for themselves and others, while respecting and preserving privacy.

With recent advances in health and medical technologies and research methods creating new opportunities to utilise health data, there is a significant opportunity for Australia to realise innovation and improvement in preventative health, medicine and healthcare.

These advances have the potential to drive innovation in treatment and care that will benefit millions of Australians.

However, despite numerous existing initiatives, a plethora of complex and sometimes contradictory jurisdictional, legal and ethical regulations limit the ability of researchers and clinicians to effectively access and use this data to improve care.

These are some of the conclusions of a roundtable convened by the two Academies that brought together some of Australia's leading health and medical researchers and clinicians. Participants were united in calling for a renewed and more urgent approach to coordinating health data, driven by Australia's Federal and State/Territory Health Ministers. A focused effort is required to achieve efficiencies in accessing and linking Australians' health data in a safe and secure way, which will improve translation of existing knowledge into improved medical treatments and health services.

**The Academies call upon the Council of Australian Government's Health Council comprising Australia's Commonwealth and State and Territory Health Ministers to address health data availability and linkage as a priority at their next meeting.**

### PRIORITIES FOR ACTION

Renewed and expanded action is required in the following areas:

- **Resolve regulatory barriers limiting timely access to existing population and health data collected at state and national levels.** In this context, Australia can learn from jurisdictions such as Scotland, Canada and New Zealand. In addition, better access to private sector held data will help resolve inefficiencies.
- **Enhance medical and community understanding of and protocols for safe and ethical collection, storage, synthesis and analysis of health data.**

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- **At Commonwealth level build upon successful State-based linkage programs** such as the Public Health Research Network.
- **Develop new approaches to accessing and utilising data from novel sources**, including the Internet of Things, social media and wearables.
- **Ensure continued engagement with and respect for Indigenous data sovereignty.**
- **Further improve the quality and reliability of health and medical data collections.**
- **Bolster efforts to generate a data-skilled clinical and research workforce** through expanded professional and post-graduate training programs.

With the full rollout in 2019 of My Health Record and a recent Productivity Commission report on Data Availability and Use, Australia has a need and an obligation to ensure that Australians' health data is used efficiently and appropriately to improve medical treatment and healthcare. The Academies stand ready to assist in this important and urgent task.

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