



Senate Standing Committee on Community Affairs Legislation Committee
Parliament House, Canberra ACT

Submission to the Senate Community Affairs Legislation Committee

Inquiry into the My Health Records Amendment (Strengthening Privacy) Bill 2018

Research Australia is pleased to have the opportunity to make this submission to the Inquiry.

Research Australia supports the proposed amendments. It is critical that Australians have confidence in the My Health Record (MHR) and the way the information can be used; the proposed amendments achieve this. By requiring a court order before a record can be obtained by a third party such as a law enforcement body, the proposed amendments reflect community expectations about the core purpose for which MHRs exist and how the use of an MHR beyond the core purposes should be handled.

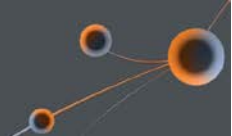
As an opt out model, it is important that Australians have confidence in the MHR and that as many as possible are prepared to participate. While the scheme is still in development, Research Australia believes that the MHR will facilitate the future delivery of safer, higher quality and more effective care to individuals; the greater the number of Australians who have an MHR the greater the number who will benefit.

Participation in the MHR will also bring benefits that extend beyond the individual. The promise of safer, higher quality and more effective healthcare has the potential to reduce the burden on our health system and improve the overall health of Australians. This, in turn, provides economic benefits by reducing the cost of delivering healthcare and increasing productivity.

The significant benefits to the broader health system and community of making better use of health data are well recognised, including by the Australian Productivity Commission.

More generally, administrative data — including performance data, patient health records and government-held datasets on patients' use of medications or procedures — can support development of a more rigorous evidence base on the clinical and cost effectiveness of health interventions. Among other things, these data (subject to appropriate privacy safeguards) enable researchers to investigate the burden of disease, access to health care across the community, and the effectiveness of specific health interventions. This can help health care providers to choose the best treatments for individual patients. It also helps governments and insurers to make better overall funding decisions by directing funding to where the greatest health benefits can be achieved (including to preventive health measures), and away from interventions with low or no clinical value.¹

¹ Productivity Commission 2015, *Efficiency in Health, Commission Research Paper, Canberra*. p.75



Since this report on efficiency in health, the Productivity Commission has undertaken a more general inquiry into the availability of public data, which again highlighted the particular benefits of making appropriately deidentified health records available for research purposes.²

The Government is currently acting on the Productivity Commission's recommendations and creating a new legislative framework to facilitate the secure sharing and release of Australian Government datasets of deidentified data for research purposes. This new framework includes the creation of a National Data Commissioner and a process of accreditation of researchers as trusted users.³ This broader data framework dovetails well with the specific provisions in the My Health Records Act for the release of deidentified data by the System Operator to researchers.

History tells us that human health has made huge advances when medicine intersects with mathematics and data. Research Australia has undertaken annual opinion polling since 2003 on matters relating to health and medical research, the health system and healthcare. We have asked questions on many occasions over the years about the use of personal health information for research purposes, and responses have been consistently positive.

It is clear that the majority of Australians understand their health and medical information can be a valuable source of data for research that can improve lives, and are supportive of its use in this way. In our most recent polling conducted in June 2018, just before the launch of the MHR Opt Out campaign, we asked people specifically about the use of MHR data for research purposes. 44% of people strongly supported the use of patients' deidentified medical records by health and medical researchers, and a further 46% we somewhat supportive.⁴

In opinion polling in 2017 we took a different approach, asking people who they trusted to have access to their health information. Health and medical researchers were rated as very highly trusted by 24% and highly trusted by 43%; almost as much as the health professionals we rely on to treat us.⁵

Research Australia is confident that the public's trust in health and medical researchers is well placed. We look forward to the amendments to the My Health Records Act addressing public concerns about access to data which might otherwise encourage individuals to opt out of the MHR, to the detriment of their own health and the broader Australian community.

Yours sincerely

Nadia Levin
CEO & Managing Director

Dated 13 September, 2018

² Productivity Commission 2017, *Data Availability and Use*, Report No. 82, Canberra See in particular Appendix E Case Study: Health Data

³ <https://ogpau.pmc.gov.au/commitment/21-release-high-value-datasets-and-enable-data-driven-innovation>

⁴ Research Australia, *Australia Speaks! 2018 Opinion Polling for health and medical research*

⁵ Research Australia, *Australia Speaks! 2017 Opinion Polling for health and medical research*

About Research Australia

Our vision: Research Australia envisions a world where Australia unlocks the full potential of its world-leading health and medical research sector to deliver the best possible healthcare and global leadership in health innovation.

Our mission: To use our unique convening power to position health and medical research as a significant driver of a healthy population and contributor to a healthy economy.

Our role:

Engage

Australia in a conversation about the health benefits and economic value of its investment in health and medical research.

Connect

researchers, funders and consumers to increase investment in health and medical research from all sources.

Influence

government policies that support effective health and medical research and its routine translation into evidence-based practices and better health outcomes.