

THE SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE FOR INQUIRY AND REPORT: THE MY HEALTH RECORD SYSTEM

Submission

Population Health Research Network

14 September 2018



ABOUT THE PHRN

The Population Health Research Network (PHRN) is a national data linkage infrastructure network. The PHRN commenced in 2009 and is funded by the Australian Government's National Collaborative Research Infrastructure Strategy (NCRIS), with support from state and territory government agencies and academic partners. The University of Western Australia is lead agent for the PHRN. The PHRN's primary purpose is to build and support the operation of collaborative, nationwide data linkage infrastructure capable of securely and safely linking data collections from a wide range of sources including within and between jurisdictions and across sectors and providing access to linked data.

Through the support of the PHRN, Australia now has the facilities and capabilities to link and provide access to linked data in all jurisdictions. This infrastructure is of international significance. PHRN achievements include:

- Establishment of new data linkage units in Queensland, Victoria, Tasmania and South Australia
- Establishment of an accredited Commonwealth Integrating Authority at the Australian Institute of Health and Welfare (AIHW)
- New online application and secure data delivery systems which facilitate access to data
- Establishment of a remote access data laboratory (SURE) that enables researchers to access linked datasets in a secure environment from anywhere in Australia

The PHRN infrastructure supports the linkage of data collections from both the public and private sectors across a range of disciplines including health, education and social services e.g. hospital admitted patients, cancer registries and the Australian Early Development Census.

The PHRN and its participants have decades of experience in operating safe and secure, national data linkage infrastructure. More than 80% of research using linked data in Australia uses the PHRN infrastructure.

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THE MY HEALTH RECORD SYSTEM

SUBMISSION TO THE SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE FOR INQUIRY AND REPORT

1. Summary of Recommendations

The PHRN makes the following recommendations:

2. The *My Health Records Act 2012* should be amended to allow for research aimed at improving health care and health care systems consistent with the *Privacy Act 1988 (Cth)* and the Guidelines under sections 95 and 95a of the *Privacy Act 1988 (Cth)*.
3. The Australian Digital Health Agency and Australian Government Department of Health should implement ongoing activities to ensure community involvement in and support for the use of My Health Records system data for improving health care and health care systems.

2. Response to the Terms of Reference

The expected benefits of the My Health Record system;

The primary purpose of the My Health Record system is the provision of healthcare to individuals.

“The My Health Record system is a system for making health information about a healthcare recipient available for the purposes of providing healthcare to the recipient.”

However, there are a range of other benefits to the Australian community which could come from research and analysis of the data at the population level.

The nature of the Australian health system means that different health data is collected by the Australian Government, state/territory governments and the private sector. Bringing this data together has not been easy to achieve due to the complex web of legislation across the jurisdictions as well as data custodians’ risk averse attitudes. Linking general practice data to hospital, MBS and PBS data has been particularly difficult. The My Health Record combines service data from across the system at the individual level and creates an opportunity for significant public benefits.

These benefits include improved understanding of:

- the use, cost and effectiveness of health services and the whole Australian health system
- complete patient pathways, care and outcomes

- the causes of complex diseases
- outcomes and safety of therapeutic interventions both during clinical trials and after interventions have entered the market

The benefits are clearly acknowledged by the inclusion of “*to prepare and provide de identified data for research or public health purposes*” as one of the functions of the System Operator and the development of the “*Framework to guide the secondary use of My Health Record system data*”.

Whilst the current Act and Secondary Use Framework acknowledge these benefits it is important that they are re-iterated in the context of the negative community response to the opt-out approach and access to My Health Record data for other purposes e.g. law enforcement.

Recommendations

1. The *My Health Records Act 2012* should be amended to allow for research aimed at improving health care and health care systems consistent with the *Privacy Act 1988 (Cth)* and the Guidelines under sections 95 and 95a of the *Privacy Act 1988 (Cth)*.
2. The Australian Digital Health Agency and Australian Government Department of Health should implement ongoing activities to ensure community involvement in and support for the use of My Health Records system data for improving health care and health care systems.

Privacy and security, including concerns regarding:

i. the vulnerability of the system to unauthorised access,

ii. the arrangements for third party access by law enforcement, government agencies, researchers and commercial interests, and

iii. arrangements to exclude third party access arrangements to include any other party, including health or life insurers;

The *My Health Records Act 2012* restricts access to My Health Records data for research to de-identified data only. We note that the term ‘de-identified’ is not defined in the Act. The use of this term may give the community the false impression that there is no risk of identification from data where names and addresses have been removed.

This restriction will also likely limit the possibility of achieving the benefits described above including the ability to conduct high quality probabilistic linkage between My Health Record data and other data collections and important research which cannot be conducted without identifiable data e.g. use of full date of birth in perinatal research.

The arrangements for access should be clear, transparent and proportionate to the level of risk to the individuals and communities whose data is being accessed. Access to any unit record (person level) data should only be granted if it can be demonstrated that the benefits of the use outweigh both the risks to the individuals/communities whose data it is and the risk of undermining confidence in the health system generally. The Five Safes Framework would be supported as the overarching approach to managing the risks of access to My Health Record data.