

NATIONAL HEALTH (PRIVACY) RULES 2018 REVIEW

Submission to the Office of the Australian Information
Commissioner (OAIC)

Population Health Research Network

4 June 2021



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.

Our Roles

- We are a respected, independent and trusted broker, valued for bringing governments, organisations, individuals and data together securely.
- We collaborate to enhance and maintain significant, innovative research infrastructure to improve the nation's data linkage capability.
- We facilitate and grow the use of linked data in the areas of health and human services.
- We advocate for an improved authorising environment for better access, use and sharing of data.
- We support the whole of government focus on accessing, sharing and using data for the national good.

Our Vision

Linking life data to improve the wellbeing of all Australians

Our Mission

To lead and enable the linking of data for world class, action-oriented research

Dr Merran Smith

Chief Executive

08 6488 8686

merran.smith@uwa.edu.au

www.phrn.org.au

NATIONAL HEALTH PRIVACY RULES 2018

PHRN Submission to the Office of the Australian Information Commissioner (OAIC)

Introduction

The PHRN welcomes the opportunity to make this submission to the Office of the Australian Information Commissioner.

The PHRN supports the review of National Health (Privacy) Rules 2018 (the Rules) given changes in information technology and data security capability and attitudes to government data sharing. The PHRN strongly supports the ongoing use of MBS and PBS data for research.

Our submission may be made publicly available.

Submission

The National Health (Privacy) Rules 2018 (the Rules) as they currently stand allow the disclosure of claims information for medical research. We advocate for the Rules to continue to support research. We recommend changes to admit for altered technology (increased cyber security and secure environments), and to encourage faster and more efficient access to data to enable research outputs to inform policy.

Restrictions on linking MBS and PBS data: Disclosure of claims information for medical research

The Rules permit Services Australia to disclose claims information to researchers for the purpose of medical research in certain circumstances. Claims information that identifies an individual may only be disclosed with that individual's consent or in compliance with the guidelines issued by the National Health and Medical Research Council (NHMRC) under section 95 of the Privacy Act.

Presently there are restrictions in both legislation and subordinate legislation that strictly constrain the linkage of MBS and PBS data. Data linkage technology has transformed significantly in the last few decades, and the technologies available to protect privacy have increased dramatically. As technology has increased and researchers have become able to conduct more complex analysis of combined datasets, the demand for linked data has also grown. This requires a revision of the restrictions that have been placed on this data.

The current approach creates a number of issues for researchers, including negative impacts on the timeliness, quality, and completeness of data, significant delays in researcher access to data, significant costs to the research team, and subsequent loss of the true value of the data. MBS and PBS data are of such fundamental importance for health service planning and research, as well as evidence-based care, that easier access to the data via more standardised processes is critical.

Interaction with the APPs

There seems to be no reason why MBS and PBS data should be subject to different or more stringent privacy regulations than any other personal health information in regard to its use for research. Australia as a long

record of safely using personal health information for research in compliance with the section 95 Guidelines and the National Statement on Ethical Conduct in Human Research.

We recommend that no additional requirements should apply to the use and disclosure of MBS and PBS data for medical research over and above the APPs including provisions for consent, waiver of consent and ‘opt-out’ approaches.

Old information

The requirement to store old information separately from newer information and MBS from PBS has had the effect of making application and approval processes for access to MBS and PBS data for research more complicated. This significantly hampers the conduct of important research in the public interest.

We recommend that the provisions in the Rules specifying separate storage of MBS and PBS data, and that old information be treated differently, be dropped.

Disclosure of claims information for medical research

Current processes used by Services Australia for release of data for research with consent appear to go beyond the requirements of the Rules, section 95 Guidelines and the National Statement on Ethical Conduct in Human Research. The current requirements for providing evidence of consent to Services Australia for research studies are inflexible and inconsistent with the consent requirements of the National Statement, particularly the following sections:

2.2.3 This information must be presented in ways suitable to each participant (see paragraph 5.2.17).

2.2.4 The process of communicating information to participants and seeking their consent should not be merely a matter of satisfying a formal requirement. The aim is mutual understanding between researchers and participants. This aim requires an opportunity for participants to ask questions and to discuss the information and their decision with others if they wish.

5.2.17 Information about research should be presented to participants in ways that help them to make good choices about their participation, and support them in that participation. These ways must take into account:

- (a) whether the information is best communicated through speech, writing, some other way, or a combination of these;*
- (b) the need for accurate and reliable translation (written and/or oral) into a participant’s first language or dialect;*
- (c) culture and its effects on how language (English or other) is understood;*
- (d) educational background and level;*
- (e) age;*
- (f) visual, hearing or communication impairment.*

In addition, Clause 12(2) of the Rules requires that even when a research participant has provided consent for future research uses of their MBS and PBS data in line with the requirements of the National Statement (2.2.14) the data must be destroyed at “the conclusion of the project”.

We recommend that clause 12(1) is kept, acknowledging that it reflects obligations that already apply under the Privacy Act and related laws. However, the inclusion of this provision clarifies that claims information may be used for medical research purposes. We recommend that clause 12(2) is deleted as it adds unnecessary limitations on research use.

Advancements in the ability to link data across multiple sectors has also opened new opportunities for the use of MBS/PBS data in population research that extend beyond the traditional medical research to environmental and social determinants of health.

We support the release of MBS/PBS data for research that may not traditionally be classified as medical research.

Use of claims information

The highest quality linkage for research purposes is only achieved using identifiable data and linking on an enduring basis. The disposal of links after every MBS and PBS linkage is delaying important research and limits Australia's ability to respond to health emergencies such as the COVID 19 pandemic. The constant re-linking of the same data is resource intensive and wasteful. The increasing volume of data in the MBS and PBS databases means that these non-enduring linkages must be re-established constantly. This is resource intensive for the Australian Institute of Health and Welfare and the Department of Health, and frustratingly slow for the researchers. Timeframes for receipt of data from these databases can be between two to three years. This reduces the impact of the research on clinical practice and health policy and hampers the response to health crises nationally.

We recommend that that the Rules allow enduring linkage of MBS and PBS data for research purposes.

Name linkage

Australia now has a very mature national data linkage system¹ which is based on gold standard probabilistic data linkage using identifiable data such as names, addresses and dates of birth. This linkage is conducted in specialist data linkage units with extremely high levels of data security and compliant with the relevant privacy and data sharing legislation. Linked MBS and PBS data are essential to understand the health of Australians and to plan for better services and facilities.

We recommend that a new purpose for name linkage of MBS and PBS data is added to clause 14(1) to make clear that name linkage for the purpose of research is allowed.

¹ See <http://www.phrn.org.au>