

National Digital Health Strategy Consultation

Submission from the Population Health Research Network

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What are your organisation's priorities in respect to digital health or eHealth?

The PHRN supports world-class research through linkage of Australian population data using methods and procedures that minimise risks to privacy.

PHRN is the key body that assists data linkages to occur, as a trusted independent and expert body with relationships with federal and state agencies and other participants in the sector.

Importance of linked data for research

For much population health and health services research, data from a single data collection is not sufficient for accurate and meaningful results. Over a person's lifetime, from birth to death, different government and private agencies collect information about health and well-being. Nowadays individuals also collect a range of information about themselves on digital devices e.g. wearable fitness trackers. It is necessary to link together these records from different sources to understand the complex pathways to both health and disease as well as the interactions between different parts of the health system. For example to understand cancer survival rates, the cancer registry data must be linked to death data.

It is necessary to use identifiable information to make the links between data collections. High quality (probabilistic) linkage involves the use of linkage variables such as name, address and date of birth. The use of unique identifiers such as the Individual Healthcare Identifier (IHI) in addition to other linkage variables will enhance the quality of linkage. In Australia the linkage of data collections is conducted by specialist data linkage units in a privacy preserving way which means that researchers can analyse the linked data without needing access to personal identifiers¹.

How could data and technology be better used to improve health and wellbeing?

The evaluation of linked population health data collected by governments, the private sector and researchers provides a more complete picture of the health of the community than is possible using other methods. As the uptake of the My Health Record increases it will become an extremely valuable population health research resource.

The types of population health research that can be conducted using these data collections include the:

- evaluation of health services
- evaluation of the safety and efficacy of pharmaceuticals
- efficacy of health interventions such e.g. immunization
- forecasting of future health care needs and development of cost effective solutions

This type of research is essential to improve understanding of the health and well-being of the Australian community, to monitor and improve the operation of the health system and to enable better decision-making by governments.

Linked population data collections are an important national resource and their re-use by researchers can bring enormous social and economic benefits.

¹ <http://www.phrn.org.au/about-us/data-linkage/how-is-data-linked/>

What are the barriers or obstacles to innovation in health and care?

The major barrier to the use of the My Health Records data in research is legislative.

The My Health Records Act 2012 specifies that the provision of data for research or public health purposes is a function of the System Operator (section 15), and makes provision for Rules to be made in relation to this function (section 109). Unfortunately these provisions relate solely to 'de-identified data'.

This specification of de-identified data is not consistent with section 24 of the *Individual Healthcare Identifiers Act 2010* (the IHI Act) which permits an IHI to be disclosed by a healthcare provider as part of the 'communication or management of healthcare information' for the purpose of research (approved by a Human Ethics Research Committee). The emphasis on 'de-identified data' is also not consistent with the *Privacy Act 1988* and the National Statement on Ethical Conduct in Human Research which both recognize the benefits of research uses of personal information and allow for its use for research if certain conditions are met including that the public benefits of the research justify the risks of not seeking consent.

Currently the System Operator is only authorized to provide 'de-identified data' for research. This precludes the possibility of the My Health Records data being linked to other data collections for research purposes as identifiable information is necessary for high quality linkage. This significantly limits the value of the My Health Records data for research and the benefits that could be realized.

Consideration should be given to amending the *My Health Records Act 2012* to include clear authority to use and disclose personal information for research as well as procedures to release data for research.

In the experience of the PHRN this issue is best dealt with in legislation. A change to an opt-out approach makes the My Health Records data collection a data collection authorized by legislation (a statutory data collection). The interaction between the statutes empowering the collection of data (e.g. the HI and My Health Records Acts), the common law and equitable duties of confidentiality and privacy statutes is extremely complex. In the PHRN's experience if the permitted uses/disclosures of the data are not clearly articulated in the authorizing legislation then it can be very difficult for data custodians (e.g. the System Operator) to make the decision to release data to data linkage units and to researchers.

The PHRN has an excellent track record in protecting privacy through the use of specialised data linkage units and secure storage of and controlled access to linked data. This model would also work well for My Health Records.

The other major barrier to innovation in health care is timely access to data for research, evaluation and monitoring. Simple procedures should be developed to ensure that My Health Record data can be used for these purposes.