ELECTRONIC HEALTH RECORDS AND HEALTHCARE IDENTIFIERS

RESPONSE TO THE LEGISLATION DISCUSSION PAPER

JUNE 2015

ABOUT THE POPULATION HEALTH RESEARCH NETWORK

The Population Health Research Network (PHRN) is responsible for the creation and operation of a research infrastructure that enables research using linked data from health data collections across all jurisdictions in Australia. The data linkage infrastructure supports the beneficial use of information held by governments for population based research to improve the health and wellbeing of Australians and enhance the effectiveness and efficiency of health services.

The PHRN was established in 2009 with collaboration between Australian state and territory governments and their academic partners to develop national data linkage infrastructure. It has received $38 million from the Australian Government Department of Education and Training through several research infrastructure programmes including the National Collaborative Research Infrastructure Strategy and the Education Investment Fund Super Science Initiative. Australian governments and their academic partners have contributed a further $51 million in cash and in-kind.

The PHRN works with all Australian jurisdictions to develop and operate safe and secure infrastructure for the linkage of health and related data contained in statutory and administrative data collections, and for the provision of this data to researchers for approved projects. This includes the capacity to link data across jurisdictional boundaries.

The purpose of the PHRN is to support the conduct and quality of population level research which can be conducted without researchers having access to personal information. The protection of privacy is, therefore, central to the rationale and activities of the PHRN.

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INTRODUCTION

The Population Health Research Network (PHRN) welcomes the opportunity to comment on the "Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper".

The PHRN's submission focuses on the benefits of using population level data for research and the opportunity for the *Personally Controlled Electronic Health Records Act* 2012 and the *Healthcare Identifiers Act 2010* to be amended to:

- acknowledge the benefits of the secondary use of this data for research
- allow records to be archived and retained indefinitely
- provide clear authority for the use and disclosure of the Individual healthcare identifiers (IHI) and Personally Controlled Electronic Health Records (PCEHR) to be disclosed and used for research
- Specify the conditions under which the IHIs and PCEHR data can be disclosed and used for research.

The benefits of using health data for research

The evaluation of health data collected by government agencies – such as births, deaths, hospital admissions and disease registries provides a more complete picture of the health of the community than is possible using other methods. The types of population health research that can be conducted using government data collections includes the:

- evaluation of health services
- evaluation of the safety and efficacy of pharmaceuticals
- efficacy of health interventions such e.g. immunization.

These types of research are essential for understanding the health and well-being of the Australian community, the operation of the health system and better decision-making by government.

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

Importance of linked data for research

For much population health 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 agencies collect information about health and well-being. 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. e.g. to understand cancer survival rates, the cancer registry data must be linked to death data. This is called data linkage.

It is necessary to use identifiable information to make the links between data collections. High quality (probabilistic) linkage involves 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 identifiers[1].

RESPONSES TO THE DISCUSSION PAPER

3.2.1 ACEH Board

The Legislation Discussion Paper proposes

> *'the ACEH Board and its advisory committees will include individuals with expertise such as:*
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> > *(a) healthcare provision;*
> >
> > *(b) consumer of health services;*
> >
> > *(c) IT systems and innovation including health informatics;*
> >
> > *(d) governance;*
> >
> > *(e) clinical safety; and*
> >
> > *(f) privacy and security.*

The PHRN is supportive of the establishment of the ACEH Board but believes that the inclusion of a member with expertise in population health research would enhance the operation and function of the PCEHR system. The inclusion of a person with research expertise would:

- assist the Board to make strategic decisions about the design and operation of the system which maximise the opportunity for the data to be used for high quality research
- demonstrate a commitment to understanding and improving the health of Australians and the Australian health system.

It is recommended that 'population health research' should be included as an area of expertise in the above list.

3.3.1 Secondary use of information

Primary care is a very important part of the health system. The Australian Institute of Health and Welfare reported that in 2012-13 38% of recurrent expenditure in health was on primary care[2]. Despite the size of the primary care system there are few population level collections of primary care information in Australia. The Medicare Benefits Scheme is the main primary care data collection but it includes very little detailed information about primary care beyond length and number of visits. If, as proposed, participation in the PCEHR became "opt-out" and there was the anticipated increased uptake of the system, the PCEHR would become an important resource for primary care research.

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[1] http://www.phrn.org.au/about-us/data-linkage/how-is-data-linked/
[2] Australian Institute of Health and Welfare 2014. Health expenditure Australia 2012–13: analysis by sector. Health and welfare expenditure series no. 53. Cat. no. HWE 62. Canberra: AIHW.

Use of the PCEHR data for research purposes is consistent with the objects of the *Personally Controlled Electronic Health Records Act 2012* (the PCEHR Act). In particular, as research undertaken using the health information in the PCEHR system can help to:

(c) *reduce the occurrence of adverse medical events and the duplication of treatment; and*
(d) *improve the coordination and quality of healthcare provided to consumers by different healthcare providers.*[3]

It is recommended that section 3 of the PCEHR Act is amended to acknowledge that the objects of the PCEHR Act can be met in varying ways including the provision of data for research purposes.

The first principle of the "Australian Government High Level Principles for Data Integration Involving Commonwealth Data for Statistical and Research Purposes" is:

Responsible agencies should treat data as a strategic resource and design and manage administrative data to support their wider statistical and research use.
This principle aims to maximise statistical and research use of existing and new Commonwealth data sets.

The PHRN understands that the PCEHR system is not currently being used for research purposes. However the *Healthcare Identifiers Act* 2010 (HI Act) and PCEHR Act both include reference to the use of the data for research and the Discussion Paper acknowledges that processes and systems need to be developed to allow the data to be used for research.

It is recommended that the first principle of the High Level Principles for Data Integration Involving Commonwealth Data for Statistical and Research Purposes should be adhered to in the development of the PCEHR system and any changes to the legislation. The amendments to legislation, processes and systems to enable the use of the IHI and PCEHR for research purposes should be developed as part of the current changes to the PCEHR and HI Acts.

The PHRN requests that it be part of any consultation or planning process to develop processes and systems for research access to the HI and PCEHR data.

3.4.8 Obligation for System Operator to retain records

PHRN notes the proposal that:

'In order to help minimise the volume of records retained by the NRS, while still ensuring that records are retained for appropriate periods for clinical and other authorised purposes, it is proposed to amend this requirement so that records are retained for the longer of:

(a) 30 years after date of death; or

(b) if date of death not known, 130 years from the individual's date of birth.'

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[3] *Section 3 of the PCEHR Act*

It may seem practical to destroy records after they are no longer clinically relevant. However, the PCEHR will be an extremely valuable source of information not just about the health journey of an individual but also about the health of families and how the health of Australians and the Australian health system changes over time.

It is recommended that the PCEHR should be retained and archived indefinitely.

3.5.3 Collection, use and disclosure of information

The PCEHR Act specifies that the provision of data for research or public health purposes is a function of the PCEHR 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 for research use if certain conditions are met including that the public benefits of the research justify the risks of not seeking consent.

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

It is recommended that the PCEHR Act should be amended 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 PCEHR 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 PCEHR 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. PCEHR System Operator) to make the decision to release data to data linkage units and to researchers.