

Submission to the Senate Inquiry into the Healthcare Identifiers Bill 2010

Introduction

This submission is made on behalf of the Population Health Research Network (PHRN). The submission addresses the following terms of reference of the inquiry:

- privacy safeguards in the Bill; and
- operation of the Healthcare Identifier Service, including access to the Identifier.

The PHRN is concerned that the terms of the Healthcare Identifiers Bill 2010 does not reflect the clear support for the use of healthcare identifiers for health service management activities and health research outlined in the Second Reading Speech and in the document *Building the foundation for an e-health future...update on legislative proposals for healthcare identifiers*. The current terms of the bill will prevent the use of 'health identifiers' for data linkage and will thus prevent their use in establishing research infrastructure that maximises the protection of privacy.

Background

The PHRN has been established to provide Australian researchers with access to linkable non-identifiable data from a diverse and rich range of health datasets, across jurisdictions and sectors. This will support nationally and internationally significant population based research that will improve health and enhance the delivery of health care services in Australia. This is an initiative of the Australian Government being conducted as part of the National Collaborative Research Infrastructure Strategy.

The PHRN is supporting establishment of data linkage capability in Australian States and Territories based on the existing capabilities in Western Australia and New South Wales. It is also developing a Centre at Curtin University of Technology to link data between States and Territories.

Data linkage within the PHRN is based on the best practice method for data linkage described by Kelman, Bass and Holman in 2002.¹ This method involves the separation of the data linkage process from the custodianship of data and the extraction of data for researchers. Identifiers such as name, address, gender, date of birth or a specific ID number are used for linkage but are not provided to researchers. Data linkage increases the ability of researchers and health managers to conduct research and monitoring without the need to access identifiable data. It facilitates the use of data for monitoring and evaluation of health services and for health research and maximises the protection of individuals' privacy. More accurate linkage is achieved by using all available means of identification.

Data linkage is conducted using identifying information, such as name, address, gender, date of birth or a specific ID number, provided by entities such as data registries and state administrative data collections. The use of 'healthcare identifiers' assigned under the authority of the Healthcare Identifiers Bill 2010 for data linkage would enhance the accuracy of linkage. The legislation in its current form, however, would not permit these entities or the service operator to disclose healthcare identifiers for the purpose of data linkage. PHRN proposes a number of amendments to the Bill which would enable healthcare identifiers to be used for data linkage.

¹ Kelman CW, Bass AJ, Holman CD, Research use of linked health data - a best practice protocol. *Aust N Z J Public Health* 2002; 26: 251-5

Recommendations

1. Part 3 Division 2 – Disclosure of health care identifier by service operator

Part 3 of the draft does not authorise the service operator to disclose the healthcare identifiers for the purposes of management, funding, monitoring and evaluation of a health service, or for the purpose of health research.

PHRN propose that a new section be inserted to authorise the service operator to disclose healthcare identifiers for use in:

- **Management, funding, monitoring, and evaluation of a health service;**
- **The conduct of research or the establishment of research infrastructure that has been approved by a Human Research Ethics Committee.**

2. Part 3 Division 3 – Use, disclosure and adoption of health care identifier by health care provider

The current wording of clause 24(2) excludes the possibility of healthcare identifiers being used for data linkage. Data linkage is conducted at research institutions and in state health departments that do not come within the definition of healthcare providers. The identifying information used for data linkage is obtained from data registries and state administrative data collections which are entities but may not be healthcare providers. The wording of clause 24(2) would not permit these entities to disclose healthcare identifiers to the research institutions that conduct linkage because an entity is only authorised to disclose a healthcare identifier to a 'healthcare provider' for the specified purposes such as research.

PHRN proposes that this section be amended to authorise an entity to disclose a healthcare identifier to another entity for the specified purposes.

The current wording of clause 24(1) permits the use or disclosure of healthcare identifiers for the purpose of 'the conduct of research that has been approved by a Human Research Ethics Committee.' PHRN is concerned that the words 'conduct of ...research' may be interpreted to exclude the use of healthcare identifiers for the purpose of data linkage. This is because data linkage can be regarded as only the establishment of research infrastructure that can then be used to conduct research. It may not itself be regarded as the conduct of research.

PHRN proposes that words such as 'or the establishment of research infrastructure' be added where appropriate to remove any doubt.

It is important to ensure that State and Territory health authorities can use healthcare identifiers for data linkage and can disclose these identifiers to their linkage authority (where applicable). It is also important to ensure that the entity undertaking linkage between State and Territory data (and possibly in the future between these data and Commonwealth data) is able to use the identifiers.

PHRN believes that these changes would reflect the e-Health objectives for health research and would be happy to provide further information if required.