

Response to the Senate Select Committee on Health Questions on Notice

Question 1 – Benefits and Barriers

Introduction

Total government health system expenditure in Australia in 2012-13 was \$100.8 billion¹. Federal and State government health system expenditure is projected to grow at an average of 6.8% per annum and will reach \$194 billion by 2022-23². A good understanding of the causes of ill health and how health services contribute to the maintenance and improvement of health is essential to properly manage this expenditure. Research can contribute to reducing health care costs by providing evidence about which services and treatments work best.

Australia has a federated health system. The country also has high quality health data collections which can be used for planning and research. However, because of the federated system, information about a person's lifetime health journey is collected and stored in many places. For example, the States and Territories collect the birth, hospital and death data and the Commonwealth collects the childhood immunisation, Medicare Benefits Scheme (MBS), Pharmaceutical Benefits Scheme (PBS) and aged care data. In order to compare national trends and to evaluate the effectiveness of health policy for government and key policy decision makers it is necessary to be able to link this information together and use it in a timely fashion.

For example a literature review on medication safety in Australia published by the Australian Commission on Safety and Quality in Health Care estimated that 2-3% of all hospital admissions are medication related. In 2011-12 the cost of medication related admissions was estimated to be \$1.2 billion³. Linked PBS and hospital admission data would provide accurate and detailed information about which sub-populations are most at risk, which medications are of most concern and the economic benefits of improved prescribing practice.

What is Data Linkage?

Data linkage is a method of bringing together information derived from different sources, but relating to the same individual or event, into a single file⁴. PHRN facilities conduct data linkage in a way that protects individual privacy. The facilities use the "separation principle" where personal identifiers are used by a specialist data linkage unit to create links between different data sources. The data linkage unit does not have access to the other portion of the record containing the health or other data (known as content information) which generally remains with the data custodians.

¹ Australian Institute of Health and Welfare 2014. Health expenditure Australia 2012–13. Health and welfare expenditure series no. 52. Cat. no. HWE 61. Canberra: AIHW.

² Extrapolated returns from investment in medical research future fund (MRFF). October 2014. Deloitte Access Economics Pty Ltd

³ Roughead E, Semple S & Rosenfeld E, August 2013, Literature Review: Medication Safety in Australia. Australian Commission on Safety and Quality in Health Care

⁴ Hobbs MST, McCall MG. Health statistics and record linkage in Australia. *J Chron Dis* 1970; 23: 375-81.

Researchers wishing to access linked data must undergo a stringent application process requiring approval from each data custodian and also from a human research ethics committee that certifies that the study is valid and in the public interest.

Once a project is approved the data linkage unit creates Project Linkage identifiers (IDs) that are specific for the approved study. The data custodians extract the required records from their collections and replace the personal identifiers from each record with a matched Project Linkage ID. The researcher is then provided with the de-identified content data by each data custodian.

Barriers

Linked Commonwealth and State/Territory health data could be used to inform most of the terms of reference of the Senate Select Committee on Health including:

- a) the impact of reduced Commonwealth funding for hospital and other health services provided by state and territory governments, in particular, the impact on elective surgery and emergency department waiting times, hospital bed numbers, other hospital related care and cost shifting;
- b) the impact of additional costs on access to affordable healthcare and the sustainability of Medicare;
- c) the impact of reduced Commonwealth funding for health promotion, prevention and early intervention;
- d) the interaction between elements of the health system, including between aged care and health care;
- e) improvements in the provision of health services, including Indigenous health and rural health;
- f) the better integration and coordination of Medicare services, including access to general practice, specialist medical practitioners, pharmaceuticals, optometry, diagnostic, dental and allied health services; and
- g) health workforce planning.

Australia has high quality health data collections and the national infrastructure to safely and securely link Commonwealth and Commonwealth/State/Territory data to provide information that will inform development of health policy, monitor policy implementation and better manage the growth in health care expenditure. Despite this capacity, significant barriers to access Commonwealth linked data remain. These include limited information in the public domain on how to obtain approval to access data as well as the limited extent of linked Commonwealth health data resources.

With respect to linked Commonwealth data resources, it can take many months to link data from the large Commonwealth data collections for a specific project and these links are generally destroyed when the project is complete. All States and Territories now have enduring links between their core health data collections. There are not enduring links between Commonwealth health data collections. In fact there are barriers to linkage of two major Commonwealth data collections, the MBS and PBS collections (see Question 2 below for further information). Ongoing linkage between Commonwealth, State and Territory health data

collections is also rare. Note that the Commonwealth and Western Australia did have an arrangement which commenced in 2002 and permitted enduring linkage of core health data collections but these links have not been maintained. Allen et al (2013) suggest that there is a risk-averse culture in Commonwealth departments which focuses on privacy risks and may not place sufficient weight on the benefits of the research findings and the risks of not doing the research⁵.

Recommendations

It is recommended that:

- 1.1 Clear, easy to follow information about required processes to apply for linked Commonwealth health data for research purposes is available on a public website(s) such as the Department of Human Services, Department of Health or AIHW.
- 1.2 The Australian Government should consider mechanisms to enable enduring linkage between its core health data collections and facilitate linkage between Commonwealth, State and Territory data collections.

Question 2 - Legislative blockages to better research in the health area

The MBS and PBS data collections are particularly important as they are the largest population-level primary care and pharmaceutical data collections. Primary health care and general practice prescribing also directly impact on rates of emergency department attendance, hospital admissions and patient health outcomes. The collection, storage and use of the MBS and PBS data is governed by the *Health Insurance Act 1973* (Cth), the *National Health Act 1953* (Cth) and the Privacy Guidelines for the Medicare Benefits and Pharmaceutical Benefits Programs issued by the Privacy Commissioner under section 135AA of the *National Health Act 1953* (Cth).

The potential benefits to the health of Australians and to the effectiveness/efficiency of health care services that can be derived from the analysis of PBS and MBS data can only be achieved if these data collections can be linked. Data linkage can now be conducted securely and using methodologies which are highly protective of individual privacy. However, the current wording of the legislation and the related Guidelines is creating uncertainty about whether it is permitted to link the MBS data and PBS data for population-based planning, monitoring, evaluation and research. This is a serious impediment to the accurate analysis of the provision of health care in Australia.

The current legislation permits the disclosure of MBS and PBS information if the individuals concerned have given their informed consent or if the Minister certifies that it is in the public

⁵ Allen J, Holman CD, Meslin EM, Stanley F. J Law Med. 2013 Dec;21(2):473-85.

interest. In practice accessing data for important health and health services research that does not have individual informed consent is difficult and there are lengthy delays in gaining approval. Clear and transparent processes are needed to ensure that applications for use of the data are determined efficiently and that both privacy and the beneficial use are maximised.

Section 135AA(5)(d) of the *National Health Act 1953* (Cth) may also be contributing to the uncertainty about whether linkage of the MBS and PBS data is permissible. It requires that the Privacy Guidelines prohibit agencies from storing MBS and PBS data in the same database. It is not clear why this provision remains in 2014 and what the purpose of the clause is.

Recommendations

It is recommended that:

- 2.1 Amendments to the Privacy Guidelines for the Medicare Benefits and Pharmaceutical Benefits Programs be considered to:
 - authorise the disclosure of identifiers from the MBS and PBS data collections for data linkage; and
 - authorise the ongoing storage of the linkage map and identifiers.
- 2.2 The Privacy Guidelines for the Medicare Benefits and Pharmaceutical Benefits Programs be amended to specify the application and approval process for access to MBS and PBS information for planning, monitoring, evaluation and research. The amendments should specify:
 - the approval criteria;
 - the timeline for response to applications;
 - that reasons be given when applications are refused;
 - a mechanism for independent review of decisions.
- 2.3 Provisions in the *National Health Act 1953* (Cth) s135AA(5)(d) related to the storage of MBS and PBS data be reviewed.