



## **Australian Government**

### **Department of Health**

28 July 2016

#### **Submission to the Productivity Commission Issues Paper – Data Availability and Use**

The Department of Health is responsible for the big data holdings of national health system data, which include Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) data, as well as a broad range of other health-related datasets. Availability of these valuable datasets for research, policy and statistical purposes is balanced against the need to ensure the privacy and security of the data relating to individuals and organisations is maintained. The Department considers these public sector datasets as highly valuable and highly sensitive and to this end we have developed data sharing policies that aim to realise the potential value that is captured in the national asset that is Commonwealth health data, while protecting privacy.

The Department has a range of data policies including the Data Access and Release Policy which was developed to ensure the Department's policies are consistent with the Australian Government Principles on Open Public Sector Information and the Freedom of Information Act 1982. A key focus of the Data Access and Release Policy is for the department to be proactive in making as much information available as is possible, while recognising and managing privacy risks associated with data release.

The Department of Health utilises an Enterprise Data Warehouse (EDW), which supports the storage of health data in a secure environment, where it can be accessed for reporting, research, analytical and predictive modelling purposes. The Department conducts regular and continuing information security risk assessments on the Health EDW to identify, evaluate and mitigate security risks in accordance with the Information Security Manual.

#### **Data Sharing Activities**

The issues paper asks how government agencies can improve sharing and linking of public sector data. This is an area of particular interest to the Department having recently embarked on a number of activities to support the use of data to inform research and new and better informed policy within the health portfolio.

The Department has provided MBS claim data to support the Multi Agency Data Integration Project (MADIP) led by the Australian Bureau of Statistics. This Project is conducted under the Commonwealth Data Integration Scheme and includes the following datasets:

- Medicare Enrolments Database;
- Medicare Claims Database;

- Personal Income Tax;
- Social Security and Related Information; and
- 2011 Census of Population and Housing.

The agencies that have contributed to the MADIP data, have in-kind access to the analytical resources and services of this high integrity linked data set without any access to the underlying personal information, avoiding any potential privacy issues. Health staff have access to the aggregate data and analytical services from MADIP directly in the ABS, and into the future will have remote access to this.

It is envisaged that development of the linked dataset and integration of additional health datasets will provide a foundational resource to which other data is intended to be added in the future.

The Department currently manages the complete history of MBS claims data (32 years to date) and PBS claims (26 years to date). The Department currently releases data to support approximately 200 external research projects per year. In cases where the Commonwealth health data is less than 5 years old, it can also be released by the Australian Institute of Health and Welfare (AIHW) and the Commonwealth Department of Human Services (DHS) in accordance with Health's policies.

To assist the AIHW (in their role as an accredited Integrating Authority under the Commonwealth Data Integration Scheme) in expediting the provision of linked data for research purposes, the Department has recently provided the AIHW with five years of MBS and PBS claims information and DHS has also provided the identifying data contained in the Medicare Enrolments file. This data provision is supporting the longer term construction of an enduring dataset that will allow access to the resultant aggregated data in a secure manner without risk of accessing private information. Responsible researchers will be able to look to use linked data and investigate health related issues.

The Department is also currently working in partnership with the AIHW, the New South Wales Ministry of Health and the Victorian Department of Health and Human Services to undertake a National Data Linkage Demonstration Project. This project will be considered by the AIHW's Ethics Committee to ensure the scope, privacy and associated governance arrangements are ethical and sustainable.

The Demonstration Project has gained the co-operation of all parties to provide detailed data including:

- Medicare Claims (Commonwealth)
- Pharmaceutical Claims (Commonwealth)
- Admitted Patient (NSW and VIC)
- Non Admitted Patient (NSW and VIC)
- Emergency (NSW and VIC)
- National Deaths data (AIHW)

Using the AIHW linking facility, it is intended to create an enduring linked dataset and provide the aggregated analytical and statistical resources to be provided into a central repository for use by analysts and modellers from each of the agencies involved. Led through the AHMAC National Health Information and Performance Principal Committee (NHPPC), this project will provide a unique opportunity to track a patient's journey through the health

care system and use of these health services. The outcomes and proposed next steps will be reported to NHIPPC, AHMAC and Health Ministers in mid-2017.

This project provides a good example of the current existing national policy across the Commonwealth and relevant stakeholders to continue to share data. This positive cooperation continues to build the analytical capabilities across sectors to enable greater insights into the health and interactions Australians have with the health care system.

The Department has previously released a full year of de-identified MBS and PBS data to State and Territory Health Departments for policy and planning purposes in accordance with the National Health Reform Agreement. To support this release the Department facilitated a national Community of Practice to assist in using and interpreting the data.

To this end the Department is also providing jurisdictional users of MBS and PBS data with technical and analytical support through a Health Data Technical Forum. It is envisaged that this forum will also assist with improved methodologies for analysis of the National Data Linkage Demonstration Project dataset.

The Primary Health Networks (PHNs) were established to increase the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes, and to improve coordination of care to ensure patients receive the right care in the right place at the right time. The PHNs utilise a number of health and demographic data sets configured by region and /or statistical area which are available to the general public on the Department's website. The Department continues to pursue options to strengthen the data analysis and reporting capabilities of the PHNs through the use of analytic and visualisation tools that support data mining and integration.

The Department also makes available linkable 10% samples of the MBS and PBS data for research and statistical purposes. These data are confidentialised to limit the possibility of deterministic linkage to other data collections thereby reducing the potential for re-identification of individuals or businesses through these records.

Aged care data is made available to the public through the National Aged Care Data Clearinghouse (the Clearinghouse). The Clearinghouse was established at the AIHW as a component of the Australian Government's *Living Longer Living Better* package of aged care reform measures. The Clearinghouse is an independent and centralised aged care data repository for providing aged care data to a range of stakeholders (e.g. researchers, services providers, consumers). It aims to encourage transparency and independence in aged care policy research and evaluation through the provision of data and information, subject to data release protocols. States and Territories have been made aware of aged care data availability and the Clearinghouse through NHIPPC.

Recently, a project to facilitate a range of enhancements to the Clearinghouse commenced. The aim of the project is to improve the visibility and user experience of the Clearinghouse through a range of activities throughout 2016-17.

Also, the Ageing and Aged Care Group recently engaged the Nous Group to undertake a review of ageing and aged care data privacy governance in light of government moves towards open and transparent data. This review has identified a number of areas that will be considered by the Ageing and Aged Care Group to ensure aged care data is readily available to the public whilst ensuring the privacy of individuals and organisations is retained. Ageing

and Aged Care Group will be reviewing the AIHW Clearinghouse in more detail to ensure consistent governance practices for aged care data across all points of access.

The development of the My Health Record system has helped to address information fragmentation in the health sector by allowing people to manage access to their own health information and enabling healthcare providers to have seamless access to the health data of their patients.

The Department of Health has developed a legally sound basis for the technical support to open up the My Health Record to third party developed mobile applications ('apps'). Using the apps, people will be able to provide their informed consent to either simply display their My Health Record data, or to use their data in broader analytics allowing the app service to provide them with actionable alerts and other health and wellbeing advice. This is part of a broader initiative on the part of the Department to appropriately empower people to determine how their data is used to their own benefit, and promote more meaningful use of data.

The My Health Record Act allows for secondary use of the My Health Record Data, and public consultation has commenced to develop the processes and protocols. The data which is expected to be available in the My Health Record System will be a rich set of codified clinical information across a patient's life and is considered to be of extreme value as well as highly personal. So getting the right settings through the secondary framework will be critical to leveraging this data into the future while maintaining community confidence.

### **Privacy Issues**

The issues paper pays particular attention to privacy. The Department is currently considering the recent report of the Senate Select Committee on Health – *Big health data: Australia's big potential*, which noted the difficulties of accessing MBS and PBS data, and particularly of linking it with other data sets. The Office of the Australian Information Commissioner, in consultation with the Department, is discussing a review of Section 135AA of the *National Health Act 1953*, the *Privacy Guidelines for the Medicare Benefits and Pharmaceutical Benefits Programs 2008* and any associated guidelines for the storage and access of MBS and PBS data. This work will support the Australian Government in implementing Recommendation 4 from the Senate Select Committee Report, with the aim of improving access to de-identified MBS and PBS data for the purpose of health policy evaluation and development as well as research undertaken in the public interest.

The Department continues to explore better ways of exploiting our data resources to provide better evidence-based advice to Government and help improve the health of Australians, whilst ensuring the privacy of individuals and organisations, and managing any justifiable release of protected information. We continue to develop ways to implement recommendations from inquiries such as the Senate Select Committee that suggest partnering with other countries engaged in data linking to ensure that Australian data access and linking policies and regulations are developed to world's best practice, as well as adopting the Productivity Commission's proposed principle that open access to de-identified datasets should be the default position.

### **End of Submission**