



Australian Government
Department of Health

Submission to the Senate Select Committee on Health – Public Hearing on Big Data and Data Linkage

Australia's health system is world class, supporting universal and affordable access to high quality medical, pharmaceutical and hospital services, while helping people to stay healthy through health promotion and disease prevention activities.

The Department of Health has a diverse set of responsibilities, but throughout there is a common purpose, which is reflected in our Vision statement: Better health and wellbeing for all Australians, now and for future generations. We aim to achieve our Vision through strengthening evidence-based policy advice, improving program management, research, regulation and partnerships with other government agencies, consumers and stakeholders.

As principal policy advisor to Government, the Department has access to a key government asset in the big data holdings of health insurance data (ie Medicare Benefits and Pharmaceutical Benefits data) and hospital data as well as a broad range of other datasets such as disease and screening data. The Department is exploring, in a variety of ways, better ways of exploiting these resources to provide better evidence-based advice to Government.

Between them Big Data Analytics and linkage of (uniquely identified but de-identified) data promise significant benefits in the health system including:

- Better information to inform the government's policy decisions
- A clearer picture of the real experiences of patients as they engage with the health system
- A better understanding of what works, how well, for what cost, and in what circumstances
- Earlier detection of trends – both positive and negative
- Earlier detection of anomalous behavior and deviations from expected results
- A more efficient health system, by supporting the most cost-effective treatments, strategies and interventions on broad-based independent evidence.

In this submission, the Department will outline the progress that has been recently made in data sharing and data linkage and suggest areas where further gains could be made.

The Commonwealth's [Big Data Strategy](#) and [Public Sector Data Management Project \(PSDMP\) Report](#) outline the future work by the Commonwealth Government and assists in making better use of Commonwealth data assets whilst ensuring the protection and privacy of individuals.

The use of Big Data technologies and analytics will be one of the focus areas in a broader activity that the Commonwealth Department of Health has just commenced to develop more comprehensive health analytic capabilities.

Initially the use of Big Data technologies will supplement the existing technology in the Department such as the Enterprise Data Warehouse (which provides for secure storage of health data for use across a range of health portfolio agencies) and the business intelligence

capabilities. Later stages may look at how a broader range of health data can be consolidated to develop deeper insights into the impact of health policy initiatives. As well as technological advances, the Department is also working to build the skills and capacity of its policy and data analysts as well as expanding this capacity through partnerships across and outside of government.

The Department is committed to sharing health data with jurisdictions, other Commonwealth agencies, and responsible researchers. The aim of this policy is to assist in the development of effective health policies that can lead to improvements in health service delivery, as well as to support an evidence base to assist researchers work towards new discoveries that will help achieve better health outcomes for all Australians.

The Department's policy is in line with the Commonwealth Government's election commitment to 'provide expanded access to useful public sector data'.

Public Sector Data Management Project

The Department of Health is contributing to the PSDMP which was commissioned by the Secretary of the Department of Prime Minister and Cabinet (PM&C) to deliver a roadmap to unlock the potential of public sector data to drive innovation, efficiency, productivity and economic growth.

As articulated in the PSDMP report released on 3 December 2015, the Australian Government recognises the current opportunities and challenges to harnessing the full value from public sector data. It summarises the current issues as being:

- No clear mandate for the Commonwealth to use and release public sector data
- Barriers (perceived and real) to sharing data within the Commonwealth and with jurisdictions to improve policy and service delivery
- A lack of sufficient incentives, skills and organisational arrangements to capitalise on its data
- No culture of publishing data to foster economic opportunities.

In Health these challenges include:

- Complex arrangements around data privacy and data sharing (summarised later in this submission) which impact of the use of data within and across agencies and the sharing of data outside of the Commonwealth government
- Negotiating access to data across jurisdictions
- Putting in place systems to standardise, clean, store, transfer and provide access to data from private providers of health services (eg GPs, allied health, private health insurers), which is a particular issue for better understanding of patient health status and the provision of health services in primary health care

A clearer policy framework across agencies, driven through the PSDMP, will assist with overcoming these issues. Key elements proposed in the PSDMP report include:

- Implementation of a whole-of-government data policy and governance framework
- Building and maintaining public trust
- Establishment of a trusted-access model for sharing integrated data across agencies
- Development of a Commonwealth Government high-value dataset framework to inform prioritisation and release
- Creation of a legislative environment that supports the use of data while maintaining privacy
- Building data and analytics capability

The first six months of the PSDMP will involve a process of building confidence and momentum in public sector data management and policy innovation, primarily through a series of seven high-value data driven projects. This will be followed by longer-

term structural changes in using data. The Department of Health is leading one of the seven projects, the “Better targeting of mental health services” project.

The project will explore apparent disparities in provision of mental health services and assist in better targeting these services. The project is being undertaken in collaboration with the Australian Bureau of Statistics using already linked MBS and PBS data with the 2011 Census of Population and Housing data. The proposed demonstration project aims to conduct further data linkage by expanding the dataset and using more sophisticated analytical techniques to help explain the drivers of these disparities and, if appropriate, potential targets for policy intervention. A report detailing findings of the project, including both implications for mental health policy and implications for public sector data management, will be completed in early 2016.

Other strategies the Department is pursuing to improve data linkage and sharing are outlined below.

Data Sharing with States and Territories

Clause B98 of the National Health Reform Agreement (2011) states that the Commonwealth will provide jurisdictions with reasonable access to Local Hospital Network level and Medicare Local (since replaced by Primary Health Networks (PHNs)) level health and ageing data about Commonwealth programs.

At the Commonwealth Health Council meeting of 12 June 2014, the Commonwealth Minister for Health agreed to provide jurisdictions with patient level data from the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS).

The Department developed a protocol to ensure that the release of such a large amount of data (the 2013-14 year of data provided constituted millions of lines of records) was practical, legal and importantly that the privacy of individuals was always protected.

The data were provided to each jurisdiction as a national dataset in line with a COAG Health Council decision.

To assist jurisdictions to understand and better use the data, the Commonwealth engaged the Sax Institute to provide workshops on working with these datasets and share their expertise in linking MBS and PBS data to other research datasets.

Data Sharing with Health Portfolio Agencies

The Department is a signatory to a number of national agreements such as the National Health Information Agreement and the National Health Reform Agreement which help to improve the health of Australians through provision, use of and access to information. The aim is to improve performance and reporting, support allocation of funding and support better planning and practice in health promotion, the prevention, detection and treatment of diseases and injury and health maintenance and rehabilitation.

Broadening this approach, the Department is providing the Australian Institute of Health and Welfare with 5 years of MBS and PBS data to support the construction of an enduring dataset that can be accessed in a secure manner by responsible researchers looking to investigate any health related issue. The Institute has extensive experience and skills in developing health related databases and metadata information.

The Institute will facilitate the linkage of MBS and PBS data with virtually any other data source to identify issues that might otherwise not have come to light. For example linking pharmaceutical access records to an individual’s disease history can highlight that the wrong drugs are being used in the wrong combinations to treat certain conditions. The linked and de-identified results are provided back to the researcher for further analyses and the Institute ensures that the privacy of individuals is always protected. The benefits of such an

arrangement are extensive and include an additional ability to improve the quality of Commonwealth data.

The Multi Agency Data Integration project (MADIP)

In 2010 the Secretaries Board agreed a set of principles for cross portfolio data integration for statistical and research purposes, and arrangements to support these principles. This work recognised the benefits of the integration of Commonwealth data for statistical and research purposes, but aimed to ensure that such data integration was conducted in a safe and appropriate way.

A Cross Portfolio Data Integration Oversight Board was set up and the Commonwealth data integration arrangements formally commenced implementation in July 2014. The former Secretary of the Department of Health played a key role in establishing these arrangements.

The arrangements were reviewed and a key finding was that while the Commonwealth arrangements provide a secure data integration environment, more focus was needed to access the substantial value inherent in public datasets. It was noted that a paradigm shift is required to transform the Commonwealth arrangements from protecting Commonwealth data to maximising the use of Commonwealth data.

In accordance with this vision, and led by the Australian Bureau of Statistics and the Department of Prime Minister and Cabinet (PM&C), the Department of Health is contributing Medicare benefits data to the Multi-Agency Data Integration Project. This Project will initially include the following datasets:

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

It is envisaged that the integration of these datasets will provide a foundational research resource to which other data could be added, including the addition of longitudinal information. A future candidate dataset may include the Pharmaceutical Benefits Scheme. At present, access will be to participating agencies.

The purpose of the project is to create an enduring, linked, publicly accessible research data resource which is on hand to enable the capacity of agencies and researchers to respond to nationally important cross portfolio policy and service delivery questions – thus helping to demonstrate the value of de-identified public data for these purposes.

The objectives of the project are to:

- Provide an exemplar for responding to demand for greater access to Commonwealth data for policy and research purposes;
- Provide a comprehensive data source for evidence-based policy development across areas of broad social and economic concern;
- Provide a foundational linked resource to which other data could be added, including the addition of information longitudinally; and
- Run a test case for the planned data access arrangements.

Data Access and Privacy

Access to the major collections of the MBS, PBS and Australian Childhood Immunisation Register are governed by the following legislative provisions:

- The secrecy provisions in Section 135A of the *National Health Act, 1953* and Section 130 of the *Health Insurance Act, 1973*;

- The Privacy Guidelines for MBS and PBS data enacted under Section 135AA of the *National Health Act, 1953* issued by the Privacy Commissioner; and
- The *Privacy Act, 1988*.

The Privacy Guidelines for MBS and PBS data impose limits on the way the Commonwealth can use such data. The Guidelines are generally more restrictive compared to the restrictions under the Privacy Act and limit the Department's use of the data for policy and programme analyses except under specially defined conditions. The same limits are not applied to persons and organisations who are not part of the Commonwealth (eg universities and medical researchers).

All data release for MBS data is governed under Section 130 of the *Health Insurance Act 1973*. For PBS and the Australian Childhood Immunisation Register data release is governed by Section 135A of the *National Health Act 1953*. This legislation holds the recipient of the data to the secrecy provisions of the relevant Act as if they were a Commonwealth Officer. However, this also limits the potential for shared data usage by researchers.

Commonwealth agencies outside of the Department of Health can only access the MBS and PBS data through the data release provisions of the Health Insurance and National Health Acts. This requires a public interest versus privacy determination via the provision of a Public Interest Certificate, and also commits agencies to comply with the Privacy Guidelines for identifiable data.

The *Personally Controlled Electronic Health Records Act 2012* (the PCeHR Act) has provision for the secondary use of information contained in MyHealthRecords for government policy and medical research. A framework for access to this data that complies with this PCeHR Act and the *Privacy Act 1988* is in the early stages of development.

Other Department of Health data are collected under a range of different arrangements and access to the data must comply with these arrangements and the *Privacy Act 1988* as appropriate.

Data Releases

The Department of Health has released data for a range of health research projects during 2015. Statistics from January to November of this year are:

- 109 releases for medical research where the participant has given consent to use their records; and 90 releases of a 10% sample of PBS data to support submissions for new pharmaceuticals to be added to the PBS;
- 5 releases for medical research where there is no consent from the owner of the records;
- 2 releases to States and Territories under the COAG Health Council agreement; and
- 10 releases to Commonwealth agencies to support health policy and programme activities.

Some of these datasets are physically released through the Department of Human Services however all releases are first authorised by the Department of Health.

In early 2016, the Department also plans to make publicly available a 10% sample of linked unit record MBS, PBS and public hospital data. These data will be confidentialised in consultation with the Australian Bureau of Statistics so that no linkage keys that would allow linkage to other data collections exists, thereby significantly reducing the potential for re-identification of records.

Another initiative through which the Department is providing data to the public is the PHNs website which has been developed as a one-stop-shop that is intended to become a central point of reference for the provision of all relevant national health (and relevant demographic) data to PHNs. It will also provide links to other relevant data sources. The PHN website aims

to reduce duplication of effort in data collection and storage and improve the quality and availability of data. It will be launched in early December 2015.

The initial focus of the website will be on health related data at the SA3 level of the Standard Australian Statistical Geography and PHN level and analytical information on health that will be critical to support PHNs to undertake their regional needs assessments. Data available currently includes:

- MBS (including non-referred GP services, Allied Health Service, Mental Health and Indigenous Health);
- PBS;
- Aged Care;
- Mental Health (including Access to Allied Psychological Services and Mental Health Nurse Incentive Programme);
- Australian Childhood Immunisations Register;
- Chronic Disease (including Diabetes Care Project and Australian National Diabetes Audit data); and
- Health Workforce Data (including Health Workforce Data online data, National Health Workforce Data Set and Clinical Placement data).

The website also features a secure site, providing PHNs with access to lower level and potentially sensitive data that will give a more in-depth picture of what is happening in their regions, to assist funding and resources to be targeted more effectively. It is intended that the website will evolve over time to include a two-way communication tool allowing the exchange of information between the Department of Health and PHNs, more detailed data and sophisticated analytics, as well as broader programme tools and resources.

The International Perspective

The WHO Western Pacific Regional Office is commencing a new initiative to examine the possible secondary uses of National Health Insurance Data to assist the wider public health policy. For countries such as South Korea, New Zealand and the United States, this has included making use of advanced analytics such as data mining and clustering techniques to obtain additional value from existing data holdings, including through the use of suitably de-identified unit record level holdings.