

# Executive Summary

Australia has some of the world's highest quality and best value hospitals and primary care services. However, providing a world-class healthcare system is an expensive business. In 2013-14, the Commonwealth alone expended more than \$63 billion, the equivalent of 25 per cent of Australian Government tax revenue. Over the past decade overall health expenditure has grown at 5 per cent above the inflation rate.

In this context it is clear that new opportunities to evaluate current practices and deliver more effective and cost-efficient policies and programs should be vigorously pursued. A recent estimate by Lateral Economics suggests that Australian government held health-specific data alone could contribute up to \$5.9 billion per annum across the economy.

Data linking is the bringing together of two or more de-identified datasets to create a new, richer dataset. Using data linkage techniques, researchers, clinicians and government administrators can deepen their understandings of the ways people use the healthcare system while maintaining patient privacy. This has the potential to inform government policy making and decisions about improving health service delivery.

Throughout this inquiry the committee heard of Australia's untapped potential to link health dataset such as births, childhood immunisation, Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), hospital, aged care and deaths.

## *New opportunities for health policy development*

The Department of Health provided the committee with a long list of significant benefits which data linkage can bring to the health system including:

- Better information to inform the government's policy decisions...
- A better understanding of what works, how well, for what cost, and in what circumstances...
- A more efficient health system, by supporting the most cost-effective treatments, strategies and interventions on broad-based independent evidence.

The committee has made several recommendations aimed at improving the development of innovative, evidence-based and more cost-effective health policy, which will lead to better patient outcomes and improve the standard of healthcare in Australia.

## *Linking Commonwealth and state datasets*

Due to the shared responsibility for the development of health policy in Australia, significant quantities of health data is collected at both the Commonwealth and state levels. To fully realise the potential of linking health data, the Population Health Research Network explained the need to access de-identified Commonwealth and state data holdings:

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 [by both the Commonwealth and the states]... 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.

The committee has made several recommendations in this area aimed at streamlining data linkage across Commonwealth and state health datasets.

### ***Restrictions on linking MBS and PBS data***

Many submitters noted that significant health policy developments and medical research advances could be made if linked de-identified MBS and PBS data were more readily accessible. For example Professor Sallie-Anne Pearson, the Head of the Medicines Policy Research Unit at the Centre for Big Data Research in Health told the committee:

The linkage of PBS, MBS and other Commonwealth collections, such as those held by the Department of Social Services, can expand our opportunities to explore value, real-world use and pivotal issues such as equity of access... When I talk to consumers, they are surprised to learn that comprehensive postmarket surveillance research does not occur routinely in Australia. Why is this the case? Activity of this kind actually requires Commonwealth and state based data holdings to be linked... The currently fragmented data systems in Australia make it difficult, if not impossible, to systematically capture these impacts.

Linked MBS and PBS data is the fourth most requested data from the Australian Government. However, presently there are legislative restrictions and binding privacy guidelines that strictly constrain the linkage of de-identified MBS and PBS data.

The current privacy guidelines were made by the Privacy Commissioner in 2008 and provide that data from the PBS and MBS databases may only be linked:

- if it is necessary to comply with law;
- to determine eligibility for a benefit under one program, where eligibility depends upon services provided by the other program;
- where Medicare reasonably believes that doing so would prevent or lessen a serious and imminent threat to life or health; or
- for release where a person has provided their consent.

If linkage is undertaken for medical research purposes, the claims data can only be released where an individual has consented to having their data released and where the researcher undertakes to destroy the claims information provided to them at the conclusion of the research.

### ***Changes in technology relevant for MBS-PBS linkage***

One of the pioneers of Australian data linkage, Emeritus Professor D'Arcy Holman, has detailed the remarkable transformation technology has brought to data linkage techniques and the resultant privacy benefits:

...one might query if [data linkage] represents a significant invasion of privacy. To the contrary, the effects of data linkage on privacy have been exactly the opposite, with a profound privacy benefit compared with the way we did research before.

[Raw patient administrative data comprise] lots of documents, and now computer screens, liberally plastered with the patient's name and address. During the [1970s and 80s], I waded through countless thousands of [personal patient] records... Data linkage has turned this approach on its head...so that during the last 20 years, what I've worked with has looked like this: No names and addresses, age rather than date of birth...and just a number is used to represent each person... Nevertheless, use of the same number for the same anonymous person in each project, illuminates the crucial connections within and between different data collections, so that the outcomes can be measured.

The committee heard from representatives of the Department of Health who acknowledged the 'very strong concerns about privacy' which historically dominated departmental assessments of data requests. However officials noted the paradigm shift that has occurred:

...what has happened fairly recently is that there has been a significant cultural shift in the way data is regarded. It is regarded as an asset; it is regarded as a key tool in informing policy development and research. I think we are shifting from a culture of protecting data at all costs to one of protecting data but also identifying ways we can use it.

### ***The need for review***

The Acting Australian Information Commissioner and Privacy Commissioner, outlined his position that sometimes legislation needs to be revisited in light of technological changes:

Something that we find with a number of the laws that I deal with is that there is a need to review some of those because the situations change quite dramatically in terms of technologies you can use to bring together information sets and how they can be dispersed...

in 2011—I said that we were certainly open to having [the MBS-PBS legislative restrictions] looked at because it was, for want of a better description, an old piece of legislation that was developed at a different time when there were different community expectations and different mechanisms to simply store the information.

So what I am saying is yes—I think it is entirely appropriate to have that piece of legislation reviewed, to look for other mechanisms which may be able to make more efficient use of that information in terms of...freeing up data for good social policy purposes. But at the same time I would then say that if we are going to do that, what can we build in to ensure there is the right level of protection about that information in a newer environment of how it is going to be used?

In December 2015, the *Public Sector Data Management Report* called the current privacy arrangements 'over-cautious and cumbersome'.

The committee has recommended that the government undertake legislative and regulatory reviews of privacy arrangements with the aim of improving access to de-identified MBS and PBS datasets whilst maintaining robust and appropriate privacy protections. The committee's intention is to strengthen health policy evaluation and development as well as medical research undertaken in the public interest whilst ensuring effective protections for sensitive personal information.

By contrast, the committee believes that the government's planned privatisation of the Medicare payments system risks the unintended disclosure of sensitive MBS and PBS data and that this proposal should not proceed.

### ***Improving access to health datasets***

The committee was deeply concerned by the lack of transparency regarding the data held by government departments. If Australia is to maximise the value of its data resources, researchers need to know what data sets are available and how to access them.

During the course of this inquiry it became obvious that some departments were uncertain about what datasets they held.

It ought to be clear to both researchers and departments what data each department collects and what part of the department is responsible for data custodianship. The *Public Data Policy Statement*, the *Public Sector Data Management Report* and a chorus of witnesses all agreed that non-sensitive data should be publicly available as a right and that sensitive data should be accessible subject to appropriate privacy and security constraints. Accordingly, the committee has recommended that departments publicly list their dataset holdings on their websites and on data.gov.au. Departments should also to publish a statement that clearly explains their dataset approvals process.

The committee has also recommended that:

- by default, de-identified datasets should be released on an enduring basis;
- the government review the cost of data access and linkage;
- consideration be given to accrediting State data linkage units to link Commonwealth data with State data collections, subject to comprehensive privacy and security protocols;
- the government take a whole-of-government approach to streamlining the ethics approval process and the authorising environment; and
- departments set and publicly report on data linkage performance benchmarks.

### ***Conclusion***

Australia has the potential to significantly benefit from improved data linkage arrangements. This would lead to strengthened evidence-based policy making and advances in healthcare service delivery. The committee urges the government to seize this valuable opportunity to improve individual patient outcomes and raise the overall standard of healthcare in Australia.