

Chapter 3

Improving health policy development

Introduction

3.1 Australian governments rightly place a high priority on the health of their citizens. As a result Australia delivers some of the highest quality and best value hospitals and primary care in the world. However, a world-class healthcare system is an expensive business. In 2013-14, combined government health-related expenditure was greater than \$100 billion per annum.¹ The Commonwealth alone expended more than \$63 billion in that year, the equivalent of 25 per cent of Australian Government tax revenue.² Over the past decade overall health expenditure has grown significantly above the inflation rate at 5 per cent in real terms.³

3.2 At a time when the government is struggling to effectively manage the growing health budget, it is clear that new opportunities to evaluate current practices and deliver more effective and cost-efficient policies and programs should be vigorously pursued.

3.3 This chapter explores the new opportunity that big data provides to ensure that our health expenditure is as efficient as possible, and more importantly to improve the standard of healthcare in Australia.

The traditional approach

3.4 Witnesses told the committee that the current approach to government health policy evaluation and development lacks a firm evidence-base. For instance the Centre for Big Data Research in Health cited evidence underpinning the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) to highlight the limitations of the current approach:

Australian governments invest more than \$100 billion annually on healthcare, yet we have a relatively limited understanding of Australia's return on this investment. For example, the Medicare Benefits [Schedule] (Commonwealth spend approximately \$21 billion annually) consists of some 6000 items, but fewer than 5% have been assessed for safety, effectiveness and cost-effectiveness against contemporary evidence. Even when medical treatments have undergone extensive pre-market evaluation in randomised controlled trials, like all of the items listed on the Pharmaceutical Benefits Scheme (Commonwealth spend approximately \$9 billion annually), they are most often tested over relatively limited time

1 AIHW, *Health expenditure Australia 2013-14*, September 2015, p. viii.

2 AIHW, *Health expenditure Australia 2013-14*, September 2015, pp 15–16.

3 AIHW, *Health expenditure Australia 2013-14*, September 2015, p. viii.

frames, even if medicines are used for a lifetime, and in populations that do not represent the people using them in routine clinical care.⁴

3.5 In a recent research paper, the Productivity Commission pointed to potential negative consequences of data holders not permitting the release of administrative health data:

Concealing data can mean that patients receive ineffective (or even harmful) care, adverse effects of drugs go undetected, or significant money is spent on interventions that do not improve health outcomes (rather than on interventions that do). It can also make it difficult to hold health care providers to account for their performance.⁵

3.6 Dr Barbara Mintzes, a Senior Lecturer at the University of Sydney's Faculty of Pharmacy, gave the committee a concrete example of risks associated with the traditional approach to PBS listings:

When a medicine is first approved for marketing, we know very little about its safety, especially in the longer term. On average, drugs are approved based on the experience of around 2,000 people who have used the medicine for short periods of time. Once on the market, millions of people may use the same drug. This is what happened with the arthritis drug Vioxx [a prescription anti-inflammatory which was recalled in 2004]... In its five years on the market, Vioxx caused up to 140,000 heart attacks in the US.⁶

3.7 At a subsequent hearing, Professor Fiona Stanley who pioneered ground data-linked population health research in Western Australia in the 1970s and '80s, explained how the problems with Vioxx could have been mitigated through the use of data linkage:

I have one example around a PBS linkage to all the health outcomes... Vioxx was not picked up for a long time—perhaps for four or five years—because it caused a common outcome of heart attacks and heart-related deaths. However, if we had linked our PBS into all our health outcomes, how many deaths and serious, morbid and costly heart attacks could we have prevented in that four or five years? Hundreds and hundreds. In my opinion, not doing this linkage of PBS to health outcomes alone is actually negligent.⁷

3.8 The Australian Health Economics Society (AHES) pointed out that under current arrangements, certain 'basic questions' cannot be answered:

4 Centre for Big Data Research in Health, UNSW, *Submission 172*, p. 2.

5 Productivity Commission, *Efficiency in Health*, April 2015, pp 85–86, as cited by Research Australia, *Submission 182*, p. 9.

6 Dr Barbara Mintzes, Senior Lecturer, Faculty of Pharmacy, University of Sydney, *Committee Hansard*, 11 December 2015, p. 1.

7 Professor Fiona Stanley, AC, Patron and former Director, Telethon Kids Institute, *Committee Hansard*, 2 February 2016, p. 23.

Australia has been – and still is – lagging behind [the US, UK, Canada and New Zealand in the access and use of health care administrative data]. As a consequence, Australia has a poorer health economics and health services research infrastructure and many basic questions cannot be addressed (e.g. changes in the out-pocket payments by consumers using Medicare)...⁸

3.9 As a result the AHES submitted that Australia is foregoing 'considerable benefits in terms of understanding health system which can lead to both greater efficiency and improved health outcomes.'⁹ The AHES concluded that:

...research within government focuses on short term issues within electoral cycles and is not driven by an overarching research strategy that focuses on the key long term questions. As a consequence, key research questions and policy issues remain unanswered for decades and governments continue to revisit these issues inefficiently leading to waste.¹⁰

3.10 SA-NT DataLink highlighted the difficulties faced by state and territory governments in formulating their health policies due to the inaccessibility of Commonwealth data:

Lack of timely and affordable access to critical Commonwealth data (such as MBS, PBS, Centrelink) is a serious obstacle to developing a more informed understanding of health outcomes and services at the State/Territory levels.¹¹

3.11 Finally, the Centre for Big Data Research in Health argued that, given a multitude of modern-day pressures, the traditional approach is 'no longer adequate':

The increasing complexity of healthcare in terms of rapidly evolving and fragmented service delivery models, the disruptive impacts of new therapies and technologies, and people living longer with multiple health conditions means that traditional methods guiding health policy and practice are no longer adequate.¹²

New opportunities for health policy development

3.12 By contrast, a variety of submitters explained the significant benefits that could flow to the development of health policy if decision-makers had a more robust evidence-base.

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

- Better information to inform the government's policy decisions

8 Australian Health Economics Society, *Submission 184*, pp 3–4.

9 Australian Health Economics Society, *Submission 184*, p. 3.

10 Australian Health Economics Society, *Submission 184*, p. 4.

11 SA-NT DataLink, *Submission 181*, p. 2.

12 Centre for Big Data Research in Health, UNSW, *Submission 172*, p. 2.

- 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.¹³

3.14 SA-NT DataLink drew the committee's attention to analysis by the Productivity Commission that highlighted the critical need for evidence-based policy:

[The Productivity Commission] recognised that the ability to undertake population based research by linking administrative data held by government agencies and other bodies is essential to supporting evidenced based policy. [The Productivity Commission] strongly argued the need for systematic evidence-based policy to ensure the effectiveness of the massive expenditure in the areas of health, welfare, education and other areas of Government activity. [The Productivity Commission] regarded the demonstrable effectiveness of this expenditure in achieving the planned for outcomes as critical, particularly in periods where there are very strong budgetary pressures on Government to reduce expenditure.¹⁴

3.15 The Council of Academic Public Health Institutions Australia (CAPIA) also provided a compelling account of the benefits of linking health datasets to deliver improved health policies:

The availability and accessibility of linked data collections is vital in working towards improvements in the health of Australians and in healthcare delivery. At a population level, data linkage provides a more complete understanding of health than is otherwise possible utilising alternative research methods. Providing approved researchers with access to a range of linked State and Commonwealth health and social data has the potential for national, state and local comparative effectiveness, clinical trials and registry research that has thus far been largely untapped, to drive health policy, redesign, quality improvement and evidence translation in health care. Additionally, it enables, for example, the rigorous objective evaluation of health policy for government and key policy professionals; and the ability to compare trends nationally, to identify programs that deliver value for money and to avoid wasting resources on those that are not delivering. The result is better targeted, evidence-based and more cost-

13 Department of Health, *Supplementary Submission 155*, p. 1.

14 SA-NT DataLink, *Submission 181*, p. 5.

effective health policy, services and interventions for the Australian community.¹⁵

Linking Commonwealth datasets

3.16 Health policy development at the Commonwealth level was a key area where submitters argued that significant improvements and efficiencies could be made. For instance Dr Julian Elliott, a Senior Research Fellow at the Australasian Cochrane Centre explained that the benefits of transforming existing datasets into 'evidence-informed policymaking':

So we need to have a capacity in Australia, particularly public agencies, to use the datasets that are becoming available to really drive effective decision making, evidence-informed policymaking... It is really about how we take data and then transform that into evidence-informed, up-to-date recommendations across the whole of the health sector, whether it is policymaking at a Commonwealth level or right down to the decision of an individual clinician. We have a huge opportunity to improve that cycle...¹⁶

3.17 Dr Elliott elaborated on the benefits of using big data analytics to effectively evaluate the impact of policies on health outcomes:

...it is really about how we monitor the effect that these systems then have on the outcomes that we are interested in. Is it actually changing healthcare practice? Are we getting a return on investment for our healthcare interventions? Ultimately, what effect is it having on patient outcomes? Those elements can also be collected and understood within these data systems.¹⁷

3.18 Witnesses referred the committee to an array of important Commonwealth data sources that could be beneficially linked to support evidence-based policy development as well as providing medical researchers with valuable source data. Perhaps the most comprehensive list was provided by SA-NT DataLink which suggested the following:

PBS, MBS, Immigration, Justice, Childcare Benefits, Private and Public School Education, Higher Education enrolment and academic results, Aged care, Family Tax Benefits, Employment related data from ATO Personal Income Tax and Company Tax/ABN GST and ABS.¹⁸

3.19 Of this list, two datasets, the MBS and the PBS, were virtually universally recognised by submitters as key Commonwealth data source for linkage. CAPHIA for instance submitted that:

15 Council of Academic Public Health Institutions Australia, *Submission 173*, p. 1.

16 Dr Julian Elliott, Senior Research Fellow, Australasian Cochrane Centre, *Committee Hansard*, 11 December 2015, pp 18–19.

17 Dr Julian Elliott, Senior Research Fellow, Australasian Cochrane Centre, *Committee Hansard*, 11 December 2015, pp 18–19.

18 SA-NT DataLink, *Submission 181*, p. 10.

MBS and PBS data represent two of the most important datasets in the Commonwealth repository, as they provide information on the uptake of primary care and specialist medical services, as well as use of medicines in the community, which are not available through routinely-collected State-based data collections. When combined with other data, they can provide a rich source of information to allow analysis of clinical outcomes, effectiveness of health policy, cost-effectiveness analyses and access to services across a range of dimensions, including residential location, socioeconomic status and Aboriginality.¹⁹

3.20 The current restrictions on linking MBS and PBS data were highly commented on during the inquiry. This issue is explored in greater detail in the next chapter. A related discussion regarding several Commonwealth departments' reticence to release de-identified data to other agencies is covered in Chapter 5.

3.21 Finally, it is worth mentioning a recent Commonwealth Government initiative, the Multi-Agency Data Integration Project, which is linking a series of related Commonwealth datasets. The ABS which is leading the project submitted:

A key example of these [data custodian] partnerships is the Multi-Agency Data Integration Project which brings together, for the first time, Census data with administrative data on health, income, and social security payments, to establish a foundational, linked data resource. The project aims to create an enduring integrated data resource that is:

... A comprehensive data source for evidence-based policy development across areas of broad social and economic concern...²⁰

3.22 This initiative is further discussed in Chapter 5.

Linking Commonwealth and state datasets

3.23 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. In this regard the PHRN has recognised that:

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.²¹

19 Council of Academic Public Health Institutions Australia, *Submission 173*, p. 2.

20 Australian Bureau of Statistics, *Submission 192*, p. 2.

21 Population Health Research Network, *Answer to Question on Notice*, 9 October 2014, p. 1.

3.24 Professor David Preen from CAPHIA also noted how linking of Commonwealth and state health datasets can provide a sound evidence-base to government policy development:

Critically, the Commonwealth and state linked data provides for really robust, evidence based decision making in health care that can benefit not only the health system but also, ultimately, health consumers across the country. Also, we know it can be done effectively because there have been a lot of precedents over the last 10 years where people have used Commonwealth and interstate data successfully for research to address a number of issues that have directly informed government policy, at both a state and federal level.²²

3.25 The Centre for Big Data Research in Health spelt out some of the beneficial health outcomes that could flow from an evaluation based on linking Commonwealth and state datasets:

Data linkage, across national and state collections provides a platform for answering questions about access to, and outcomes of, population and individual health interventions, surveillance of disease and mortality, health system performance, policy impact and economic analysis. Put simply, it allows us to identify high-risk and low-value health services and high-risk population subgroups, and transfer this knowledge into evidence-based policies.²³

Examples of linked datasets

3.26 The committee received many examples of past, current or potential data linkage projects which strongly point to the benefits of the technique. One outstanding example of linked Commonwealth-state datasets was provided by researchers from the School of Public Health and Community Medicine at UNSW. Dr Heather Gidding and her colleagues are linking two Commonwealth datasets, the Australian Childhood Immunisation Register (ACIR) and the National Death Index, to de-identified health data from 1.8 million children across New South Wales and Western Australia to identify specific populations at risk of preventable diseases:

The ACIR alone is a significant resource, being one of only a handful of national population based immunisation registers. However, there is insufficient information on ACIR about each child to identify specific sub-populations at greatest risk of preventable diseases. Our study brings together a wealth of routinely collected information about each child to produce the first population-based estimates of effectiveness for vaccines continuing to cause morbidity in Australian children, a strategic priority area in the recently released National Immunisation Strategy. It is also the first population-based record linkage study in the world to provide estimates of vaccine impact in an indigenous sub-population, and identify

22 Prof . David Preen, Council of Academic Public Health Institutions of Australia, *Committee Hansard*, 11 December 2015, p. 38.

23 Centre for Big Data Research in Health, UNSW, *Submission 172*, pp 2–3.

specific maternal, infant and demographic characteristics of infants with delayed vaccination. We anticipate our findings will provide assurance of the effectiveness of vaccination in all Australian children and strengthen the rationale for improving vaccination timeliness, by quantifying its impact on disease burden.²⁴

3.27 The Department of Health is also leading a data linkage trial labelled 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 2016.²⁵

3.28 The committee understands from the Department of Health that as at 13 April the report is yet to be finalised.

3.29 The CSIRO's submission provided a highly-practical example of a data linkage project designed to improve the efficiency of our hospital system:

Our Patient Admission Prediction Tool (PAPT) shows how the use of routinely collected administrative data can be used to make hospitals more efficient. PAPT uses a model built on historical data to forecast the number of patients to present at an emergency department within a certain time and the number that will go on to need admission to the main hospital wards. Access to reliable public health care is a key foundation to Australia's social and economic well-being. PAPT is designed to make improvements in resource allocation efficiency, reduce waiting times, and increase timely access to care and is now used in a number of Queensland Hospitals and is undergoing its first trial in a Victorian Hospital...

This important study required linking data across emergency department and hospital data sets. Sets from member hospitals of The Health Roundtable were provided, in accordance with their academic policy for use of collected data for research purposes...²⁶

24 Dr Heather Gidding, Senior Lecturer and NHMRC Early Career Research Fellow, School of Public Health and Community Medicine, University of New South Wales, *Submission 185*, p. 1.

25 Department of Health, *Supplementary Submission 155*, p. 3.

26 CSIRO, *Submission 174*, p. 5.

3.30 The CSIRO's submission went on to explain how the PAPT project could be improved through access to Commonwealth hospital datasets:

Although based on 12.5 million ED records, 11.6 million inpatient episodes and 46000 hospital deaths, the [PAPT] coverage represents only 79% of Australian tertiary hospitals and 40% of all Australian Hospitals. Improving access to hospital datasets held by the Commonwealth for quantitative analysis can avoid such limitations and ensure important policy decisions are based on the most comprehensive data available.²⁷

3.31 Finally, the Australian Commission on Safety and Quality in Health Care provide a future linked health data scenario which would enable the efficient monitoring of actual care and inform safety and quality improvement:

National guidelines for the management of acute coronary syndrome (ACS) specify that patients admitted to hospital for management of ACS be discharged on five medications...

However, studies show compliance with this guideline has been shown to vary across hospitals and hospital types highlighting this as an area for potential improvement.

Linking admitted national patient datasets...to PBS datasets using anatomic therapeutical chemical codes would allow analysis of adherence to national guidelines and variation from best practice, and provide valuable information for improving care of patients with ACS. Similar analyses could be conducted to monitor guideline compliance by healthcare facilities for a range of other conditions including recommended stroke discharge medicines.²⁸

Committee view

3.32 The committee is greatly encouraged by the strong interest expressed by government agencies, data linkage organisations and medical researchers, in the potential for improving evidence-based health policy development through data linking. There is clearly a wealth of worthy health policy proposals and evaluations that will commence once access to de-identified administrative data is more readily available. The novel insights that will flow from these projects will not only enable the development of innovative, evidence-based and more cost-effective health policy, it will also lead to better patient outcomes and improve the standard of healthcare in Australia.

3.33 The committee is however concerned by aspects of the Health Department's publicly stated approach to big data. Although the department supports the government's more open data policy, and also the recognises the significant potential

27 CSIRO, *Submission 174*, p. 5.

28 Australian Commission on Safety and Quality in Health Care, *Submission 187*, p. 2. The five ACS medications are 1. Beta blocker; 2. Aspirin; 3. Anti-platelet agents; 4. Cholesterol lowering medicines; and 5. ACS inhibitors.

of big data, it appears to be taking an intentionally slow approach to utilising data linkage in developing new health policies:

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 Health 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.*²⁹

3.34 This approach appears at best ambivalent, and at worst contrary to the government's public data policy statement which declares that 'Australian Government entities will...securely share data between Australian Government entities to improve efficiencies, and inform policy development and decision-making...'³⁰

3.35 The committee also notes the Department of Health has delayed its report into the data linkage project to better target mental health services. This further demonstrates that the department is not adequately prioritising important data linkage projects.

3.36 With Commonwealth funding of \$63 billion per annum at stake and recognising the importance of improving the health outcomes of all Australians, the committee urges the Department of Health to significantly increase its focus on data linkage.

Recommendation 2

3.37 The committee recommends that the Department of Health, as a high priority, actively explore and then implement measures to advance cost-effective, evidence-based policy development through the use of data linkage.

Recommendation 3

3.38 The committee recommends that relevant government departments should include information in their annual reports which describes the processes and projects being undertaken to establish evidence-based policy based on data linkage as well as strategies they have adopted to contribute to the government's public data policy.

29 Department of Health, *Supplementary Submission 155*, pp 1–2. Emphasis added.

30 Department of the Prime Minister and Cabinet, *Australian Government Public Data Policy Statement*, December 2015, p. 2.