



THE MCKELL INSTITUTE

# Big Data, Big Possibilities

HOW AUSTRALIA CAN USE BIG DATA  
FOR BETTER HEALTHCARE

# About the McKell Institute

The McKell Institute is an independent, not-for-profit, public policy institute dedicated to developing practical policy ideas and contributing to public debate. The McKell Institute takes its name from New South Wales' wartime Premier and Governor-General of Australia, William McKell.

**William McKell made a powerful contribution to both New South Wales and Australian society through significant social, economic and environmental reforms.**

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## About the Author



### RACHEL GARCIA

**With more than 15 years managerial and professional experience in the public and private sectors, Rachel has a particular interest in health and human services policy and reform.**

Rachel is currently an Associate Director at KPMG where she focuses on transformational change management, designing and facilitating stakeholder engagement programs, change leadership and strategic communications for government and not-for-profit organisations.

Prior to consulting, Rachel was a Senior Policy Advisor in the Ministry of Health and before that a Senior Patent Attorney specialising in the area of Medical Science.

Rachel holds a Master of Business Administration (Exec) (AGSM), Master of International Development (Deakin University), and an honors degree in Medical Science (Sydney University).

## Acknowledgement

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DECEMBER 2016

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# FOREWORD

Australia is on the precipice of a new era. As the Babyboomer generation enters retirement, Australian policymakers will need to find new ways to provide the services that generation requires, within the confines of a smaller workforce to sustain expenditure. However, the rise of the collection and use of large quantities of data provides us with an opportunity to make the transition into this new era far easier.

Big data's greatest asset is its possibilities. Already big data is helping to solve some of the world's most vexing problems, as well as providing better solutions to more common issues. However this is only the beginning. Some estimates suggest we only analyse 0.5 per cent of the information that we currently collect from the plethora of sensors and internet-connected devices that are in operation today.<sup>1</sup> One challenge the world will need to address is how to better use big data for the benefit of mankind.

Australia has an opportunity to contribute towards this solution, and along the way solve some of our own issues. This report discusses the range of possibilities big data presents for healthcare, as well as the challenges big data poses in collection, linkage and protection. These problems can mostly be solved by both the Federal and state and territory governments working together to develop strategies for big data, specifically in its application for health. But stakeholders must also be engaged in this process to ensure buy-in from patients and clinicians, and to ensure the safety and security of the data is prioritised.

Working together, we will be able to use big data to advance medical and pharmaceutical innovation; we will be able to reduce wastage and improve efficiencies in healthcare delivery;

and we will be able to prioritise preventative health interventions which will lead to healthier, longer lives for all Australians. But we must work together to develop the right regulatory, legal and ethical frameworks to ensure the safety and security of our citizens, and to capture the opportunities big data promises. Working together, we can build a healthier future for all Australians; but we can only do it by working together.



**The Hon John Watkins**  
CHAIR,  
MCKELL INSTITUTE



**Sam Crosby**  
EXECUTIVE DIRECTOR,  
MCKELL INSTITUTE

# SCOPE

Every day, Australians are generating enormous quantities of health data: about their medical appointments, the medicines they take, their scans and tests and even their physical activity.

Linking these records across the entire community would be a valuable resource for medical researchers, service providers and policy makers. New medicines, devices and services could be better supported by “real world evidence” of safety, effectiveness and value – helping to sustain investment in innovation and improved health outcomes.

The technical and legislative barriers, and the community’s expectation that privacy will be safeguarded, mean that reforms must be carefully considered and well-implemented.

This report aims to explore the opportunities, challenges and stakeholder expectations to map out a path forward. Roche and Allens support the contribution of this report to the national debate.



**Svend Petersen**  
MANAGING DIRECTOR,  
ROCHE



**Jeremy Low**  
PARTNER AND SECTOR LEADER, HEALTHCARE,  
ALLENS

# THE MCKELL INSTITUTE

## BIG DATA IN HEALTH

### ROUNDTABLE: PARTICIPANTS

In May 2016, The McKell Institute in conjunction with Allens and Roche hosted a roundtable event with healthcare stakeholders to discuss the future of big data in healthcare in Australia. We would like to thank the following people for their attendance and expert advice, which has formed the framework for this report.

#### JEREMY LOW

Jeremy is a Partner and Sector Leader for Healthcare at Allens. He specialises in mergers and acquisitions, corporate restructurings and corporate governance.

#### IAN MCGILL

Ian has been a partner with Allens in Australia since 1990, specialising in complex commercial contracts, including technology procurements. His industry expertise is in the fields of technology, media and telecommunications, including privacy, data security and data governance.

#### DAVID PULLAR

David is the Manager of Government Affairs and Public Policy at Roche Australia. David has Bachelor degrees in Engineering and Commerce from the University of Melbourne, and has over ten years' experience working in pharmaceuticals and biotechnology policy.

#### CARLENE TODD

Carlene is the Director of Health Economics and Pricing at Roche Pharmaceuticals Australia. Carlene has Bachelor degrees in Commerce and Science from the University of Auckland, and nearly two decades' experience in the pharmaceutical industry.

#### HELEN TYRELL

Helen is the Chief Executive Officer of Hepatitis Australia, the peak national organisation for the viral hepatitis community organisations in Australia. Helen has worked in the healthcare sector for more than 25 years in a number of clinical nursing, management and executive positions in the UK and Australia.

#### JUSTIN KOONIN

Justin is the President of the AIDS Council of New South Wales and has worked within the LGBTI community for the past decade. He is also a trained mathematician and has worked as a consultant in the areas of predictive analytics and data science.





## SHAUN LARKIN

Shaun is the Managing Director of HCF. He also has many years experience in healthcare in Australia and overseas. He is currently a Commissioner of the Australian Commission on Safety and Quality in Health Care (ACSQHC).

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## ALEXANDER LYNCH

Alex is Public Policy & Government Relations Manager for Google Australia, dealing with issues including Google's economic contribution, data-driven innovation and machine learning. He has a background in corporate affairs consulting and national security intelligence.

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## OWEN TORPY

At the time of the Roundtable, Owen was the Head of Policy and Planning at the National E-Health Transition Authority. Previously Owen has worked for the Australian Commission on Safety and Quality in Healthcare and as a senior advisor to the Minister for Health and Ageing.

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## MARTIN SNOKE

Martin is the Policy and Research Manager at Medicines Australia. He has a PhD in health science and has previously worked as a senior economist at the Australian Department of Health.

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## CATHERINE KATZ

Catherine is the Director of Safety and Quality Improvement and Intergovernment Relations at the Australian Commission on Safety & Quality in Healthcare. Catherine has more than two decades' experience across a range of state and federal government health departments.

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## PAUL SUEBWONGPAT

Paul is a health economist with the Medical Technology Association of Australia, the national representative body for the medical technology industry. Paul has 10 years experience working across the pharmaceutical and medical technology industries.

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## RACHEL McCONAGHY

Rachel is Head of Health Network Relationships at Medibank, Australia's leading private health insurer for 3.8 million Australians. She has had a 20 year career in health spanning the public, private and not for profit sectors in Australia, Hong Kong and the United Kingdom.

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## SARA PANTZER

Sara is the Head of Government Affairs and Policy at Amgen. She has more than two decades' experience in the pharmaceuticals and biotechnology industries and was the 2013 winner of the Australian medicines industry's most prestigious award, the Pat Clear Award.

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# EXECUTIVE SUMMARY

Big data promises us a world of opportunities. It promises us the power of prediction: from improving weather forecasting<sup>2</sup> and learning about earthquakes in advance<sup>3</sup> to predicting who will win the next election.<sup>4</sup> It promises us answers to vexing problems: like how to stop the tuberculosis bacterium from developing further antibiotic resistance.<sup>5</sup> And it promises to improve the quality of our lives: from helping us to identify and prevent disease<sup>6</sup> to reducing crime.<sup>7</sup>

But in no field is big data so promising as in health. Due to the sheer size and availability of existing health databases, the rate of technological innovation and rise of personalised medicine, big data health applications have the potential to make a huge impact on how we prevent, treat and cure disease. Additionally, big data in health can drastically change how policymakers and governments manage public health, including through the better use of resources, in managing epidemics, in improving medical research and in encouraging preventative methods of disease management. Demand for healthcare is growing. It is estimated that Australian government health spending will increase from 4.2 per cent of GDP in 2014/2015 to 5.7 per cent of GDP in 2054/2055.<sup>8</sup> By 2049-50, total health expenditure is projected to be \$257 billion, with \$129 billion of this due to ageing and population effects.<sup>9</sup> And while healthcare spending is growing for older Australians the fastest, healthcare expenditure is growing across all demographics as our expectations of healthcare provision increase and people are willing to spend more, more often. This makes the role of preventative health even more important; but all health services must become more efficient and more targeted in order to account for the expected growth in demand.

'Big data' is an overarching term that describes any voluminous amount of data that can be mined for information. The rise of the Internet of Things – internet-connected sensors on everything from refrigerators and televisions to personal fitness devices – has allowed big data collection to escalate. But while we are now collecting more data than ever before, we are struggling to keep pace with managing and using that data.

In 2009, the entire Internet was estimated to fill half a zettabyte; by 2020, the digital universe is expected to grow to around 44 zettabytes. A zettabyte contains roughly 1,000 exabytes, and a single exabyte “can stream the entire Netflix catalogue more than 3,000 times”.<sup>10</sup> However, recent estimates suggest we only analyse and use about 0.5 per cent of all the data that is currently produced.<sup>11</sup> One of the challenges with big data is to find a way to manage and effectively utilise it.

This report builds upon ideas discussed at a McKell Institute roundtable hosted in May 2016. Participants discussed the challenges and opportunities presented by big data in health, and provided ideas and recommendations as to how we can effectively capture those opportunities.

This report begins with an overview of big data

in health in Australia, before outlining some of the possibilities and opportunities posed. It then discusses the challenges that are facing stakeholders and policymakers in the effective use of big data in meeting these opportunities. Finally, a series of recommendations are presented that are directed at the Federal and state and territory governments, but which will require the engagement of healthcare stakeholders in order to be fully implemented.

A majority of Australians believe that scientific research should be used to improve healthcare and are willing to share their data for this purpose, on the proviso it is kept safe and secure<sup>12</sup> and that their data is de-identified (and is not capable of re-identification). This sentiment is one that we should continue to build upon as we implement reforms to better utilise big data in healthcare.

Big data presents us with a world of opportunities, but in order to harness those opportunities, we need leadership from government and a greater level of cooperation amongst stakeholders. Most importantly, we should act swiftly to ensure the opportunities presented by big data in healthcare can be most effectively captured and we can ensure a healthier future for all Australians.

# RECOMMENDATIONS

## RECOMMENDATION 1

**The Federal Government should conduct an inquiry into the role and future of big data in health.**

The Commonwealth must engage stakeholders in this process in order to understand their perception of the role of government for data and data access. The inquiry should further investigate healthcare consumers' perceptions of the importance of maintaining privacy and their willingness to and conditions for sharing their health data, in order to find the appropriate balance.

## RECOMMENDATION 2

**The Federal Government should develop and implement a new strategy to promote collection of individuals' health data through the My Health Record.**

Ideally, the Australian Digital Health Agency (ADHA) should take the lead in raising awareness and support for the implementation of incentives for GPs and specialists to use the My Health Record. This must be implemented alongside innovations and safeguards that make the My Health Record easier to use. Consideration should also be given to implementation of gamification incentives that reward increased collection of individuals' health data with the My Health Record.

## RECOMMENDATION 3

**State and territory governments need to release more hospital performance data.**

Currently it is evident that valuable data for public hospitals is collected but not released. A review by each state and territory government should be undertaken to determine which data can be released and in which situations. The release of hospital performance data has the potential to benefit all healthcare stakeholders by disclosing best practices and efficiency information.

## RECOMMENDATION 4

**The Council of Australian Governments should immediately undertake an analytics project to link state databases with national datasets.**

Australia's healthcare system is a large, fragmented and complex network of services, providers, recipients and organisational structures provided by public and private sector health services. Information in the Australian healthcare system is captured and held by all of these various stakeholders. Public datasets are captured by the Commonwealth, States and Territories and rarely shared amongst other stakeholders. The challenge is to bring these datasets together to understand the whole patient journey.

In NSW, the NSW Data Analytics Centre has been established to undertake priority analytics projects. A priority project to link the Medicare Benefits Schedule (MBS), the Pharmaceutical Benefits Schedule (PBS) and hospital data, for example, would increase understanding of individual patient pathways and the way stakeholders use the health system as a whole. The recommended pilot would demonstrate the value of linking these datasets and provide insights to improve healthcare.

## RECOMMENDATION 5

**The Federal Government should undertake an urgent review of the legislation inhibiting the collection, linking and sharing of health data.**

As technology evolves, there are at least three primary pieces of legislation and guidance that may inhibit big data from having a positive impact on health in the future. The *National Health Act 1953* (Cth) prevents the linking of Medicare Benefit and Pharmaceutical Benefits claims information; the *My Health Records Act 2012* (Cth) restricts how health information may be collected, used or disclosed in relation to, and for the purpose of, the My Health Record system; and the *Guidelines for the Disclosure of Secondary Use Health Information for Statistical Reporting, Research and Analysis 2015* provides guidelines for National Health Information Agreement signatories about using data for secondary purposes. Additionally, the Privacy Amendment (Re-Identification Offence) Bill 2016 will have uncertain implications on the use of government datasets for improving healthcare..

## RECOMMENDATION 6

**The Federal Government should develop a secondary use framework that incorporates the Five Safes Model of data sharing.**

The model ensures safety of people, projects, settings, data and outputs; ensuring data is safely accessed and utilised by different parties and in different contexts. The Five Safes model is currently used in a variety of situations in different organisations across the world and is deemed appropriate for the sharing of health data in Australia.

## RECOMMENDATION 7

**The Federal Government must design legislation, administrative processes and policies that will simplify the access to health data collections for medical research. The policies must maintain privacy and security.**

A number of submissions have been made to the Commonwealth arguing the merit of enabling access to and linking of Commonwealth administrative databases, such as the MBS and PBS databases. Ideally the Commonwealth Government will further facilitate systematic linking with other administrative databases (for example, CentreLink); other Commonwealth health data (for example, the MyHealth Record); and State health data (ie. hospital data). This will require a review of currently restrictive legislation, administrative processes and policies that inhibit access, sharing and linking of valuable health datasets.





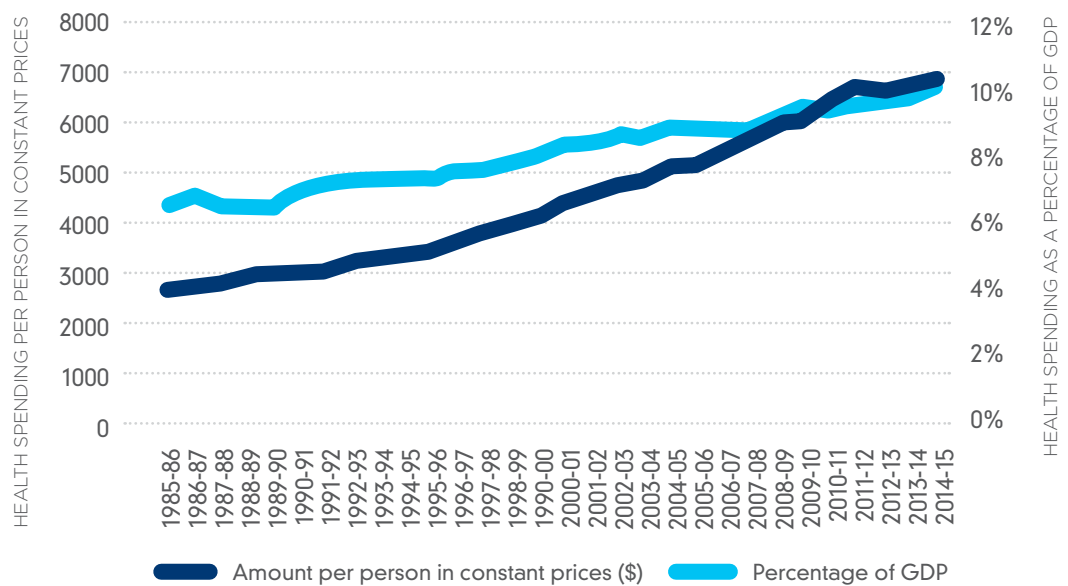
# PART ONE: TRENDS IN HEALTHCARE AND BIG DATA

By international standards, Australia is a healthy country that provides health services relatively efficiently. Overall, Australians enjoy some of the longest lives globally — the average life expectancy for males is 79.5 years and for females is 84.0 years, and Australians today can expect to live 25 years longer than our forefathers did a century ago.<sup>13</sup> Compared to the OECD, Australia's healthcare system is also one of the most efficient in terms of life expectancy achieved for dollars spent.<sup>14</sup>

However, Australia is facing an increase in the demand on our health services.

*"In 2011-12, Australia spent around \$140.2 billion on health, around 1.7 times higher in real terms (after adjusting for inflation) than in 2001-02. Health expenditure has grown faster than population growth. Expenditure increased from \$4,276 per person in 2001-02 to \$6,230 in 2011-12."<sup>15</sup>*

**FIGURE 1.1** National health spending in Australia 1985-2015



Source: Australian Institute of Health and Welfare, Health Expenditure Data, 2016

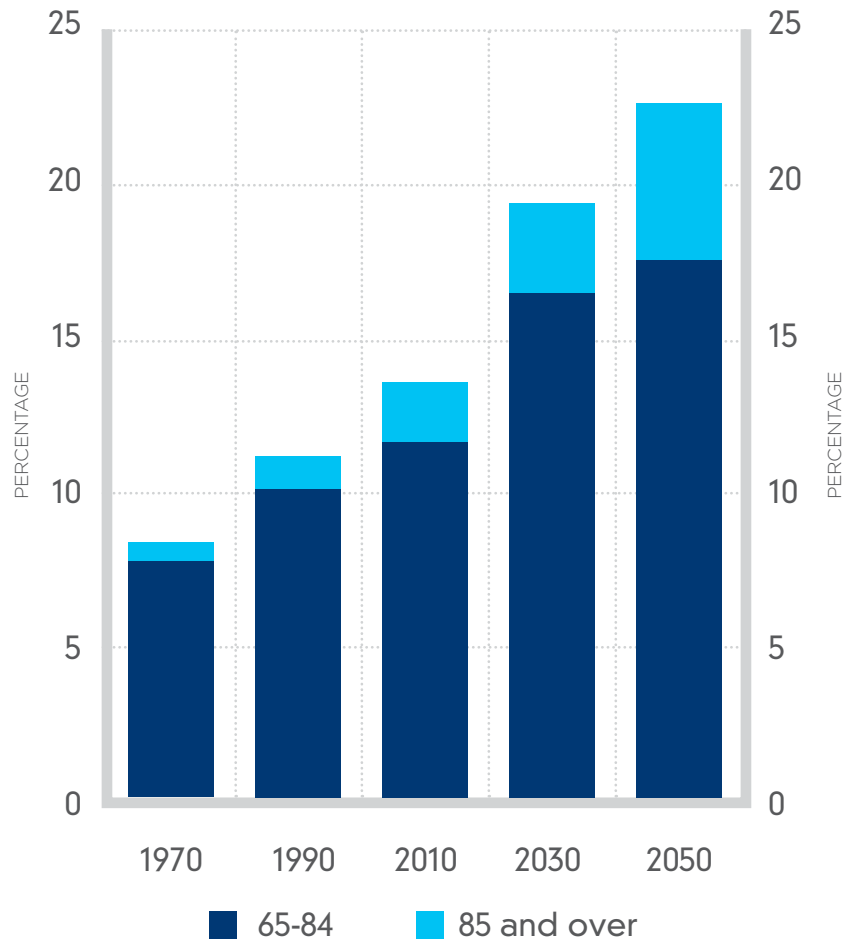
Projections for Australian government health spending suggest that it will increase from 4.2 per cent of GDP in 2014/2015 to 5.7 per cent of GDP in 2054/2055.<sup>16</sup>

The reasons for this increase in demand are multiple and complex. Two of the main reasons currently thought to contribute to this trend are (i) the ageing population and (ii) an increasing demand for expensive, high quality medical tests, treatments and technologies.

**(i) The ageing population**

The median age of our population is continuing to rise as people live longer. The Treasury’s *Intergenerational Report 2010*<sup>17</sup> reveals that as a cohort, the over 65s will represent 25 per cent of the population by 2050, up from just 8 per cent in 1971. The incidence of sickness and injury increases with age and older people consume more health services per capita. An ageing population places significant and increasing demand on health services. Moreover, the ratio of working age Australians to over 65s is decreasing, meaning there are fewer taxpayers to fund this increasing demand.

**FIGURE 1.2**  
The proportion of the Australian population over the age of 65, 1970-2050.



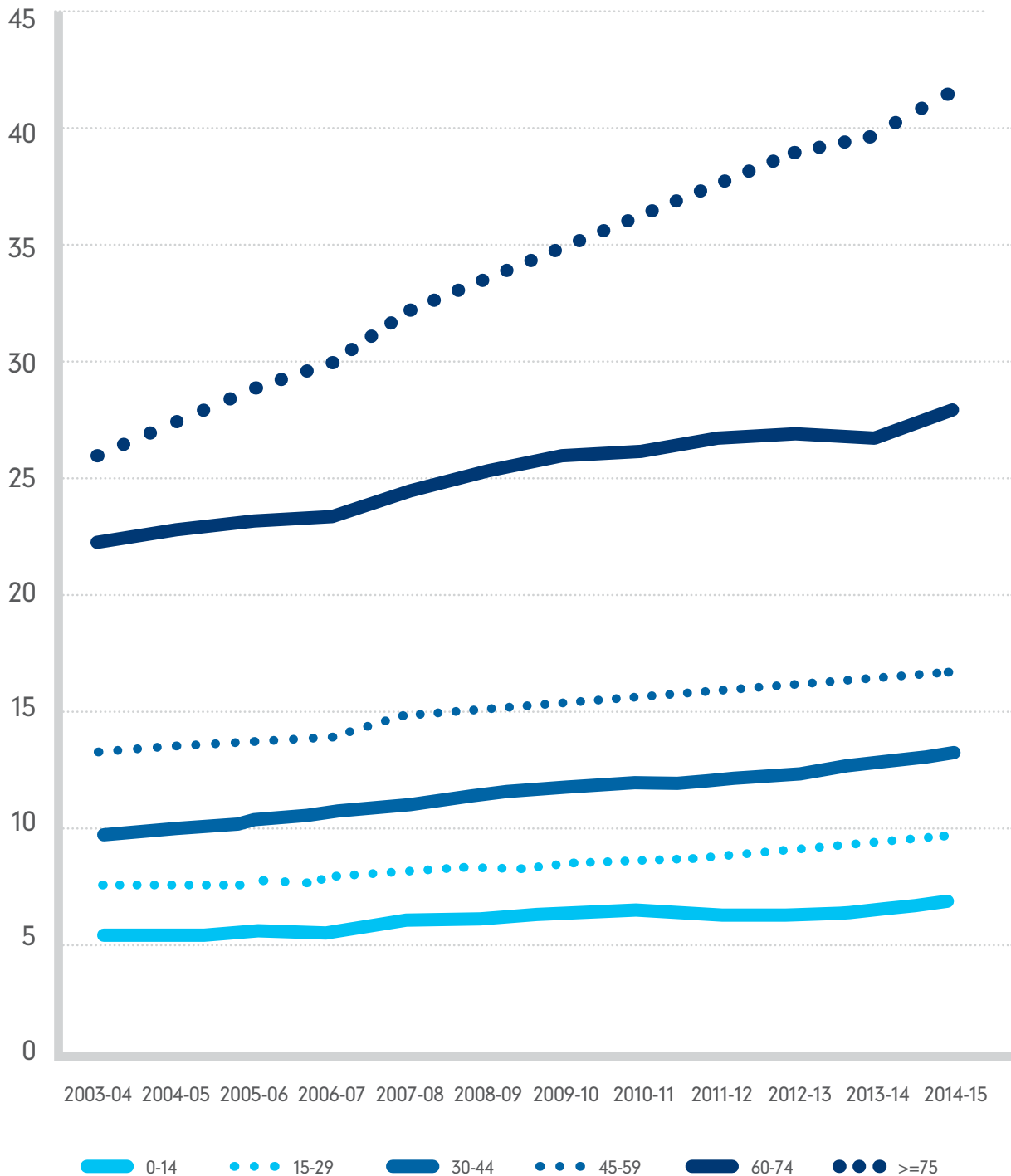
Source: Australian Government, Intergenerational Report, 2010

The Productivity Commission reports<sup>18</sup> that healthcare costs for those over 65 are, on average, around four times as high as for people under 65, and end-of-life care costs are even higher. As noted in the 2014 McKell Institute report, *Getting us there - Funding the transport infrastructure of tomorrow*, "from 2009-10 to 2049-50, real health spending on those aged over 65 years is expected to increase around seven fold. Over the same period, real health spending on those over 85 years is expected to increase around twelve fold." By 2049-50, total health expenditure is projected to be \$257 billion, with \$129 billion of this due to ageing and population effects.<sup>19</sup>

The Medicare Benefits Schedule (MBS) Review Taskforce – Interim Report<sup>20</sup> published in September 2016 reports the use of MBS services is growing at a rate that exceeds population growth, and confirms the number of services per capita is much higher in the oldest age groups compared to younger cohorts. For patients in the 75-year age group, per capita use of services increased from 25.9 to 41.3 services per person per annum between 2003-04 and 2014-15.



**FIGURE 1.3** Number of MBS services per capita per annum by age: 2003-04 to 2014-15



Source: Australian Government, Medical Benefits Schedule Review Interim Report, 2016

One specific contributing factor is that this patient cohort suffers from a growing burden of chronic conditions: older people are more likely to suffer from cancer or chronic illnesses such as arthritis and dementia.<sup>21</sup> The economic burden of chronic disease is significant. The Australian Institute of Health and Welfare reports that the four most expensive disease groups (based on healthcare expenditure) are

chronic—cardiovascular diseases, oral health, mental disorders, and musculoskeletal—and conservatively estimates that these diseases incur direct health-care costs of \$27 billion in 2008–09. This equates to 36% of all allocated health expenditure. Much of the cost comes from admitted patient hospital services, out-of-hospital services, medications, and dental services.<sup>22</sup>

**TABLE 1.1:** Common chronic diseases in Australia

Common long-term conditions in 2011-12	Persons	Percentage of population
Arthritis	3,265,400	14.8
Back pain/problems/disc disorders	2,805,500	12.7
Hypertension	2,262,000	10.2
Asthma	2,254,600	10.2
Depression	2,143,100	9.7

Source: Australian Institute of Health and Welfare, Australia's Health 2014

## (ii) Increasing demand for expensive tests and treatments

Increasing utilisation of healthcare services and the use of more expensive technologies are also contributing to increased healthcare expenditure.<sup>23</sup> People of all ages are seeing doctors more often, having more tests, treatments and operations, and are consuming more medications.<sup>24</sup>

The reason for this increase can partly be attributed to increasing expectations of the provision of healthcare: “The amount and quality of health services demanded by the community will be influenced by what is considered a desirable level of health.”<sup>25</sup> As disposable incomes increase along with real incomes, consumers of healthcare can and will demand and receive more and better quality health services.

Additionally, while advances in medical technologies provide significant benefits, they also historically contribute to increasing costs in healthcare.<sup>26</sup> Over the long term, advances in medical technologies provide value for money and are appreciated by consumers for improving quality and length of life. Still, it should be noted that cost-effectiveness varies between technologies and demographics and this can benefit from review. It is preferable that technologies be assessed for their effectiveness and need, such as through the Pharmaceutical Benefits Advisory Committee, the Medical Services Advisory Committee or the current MBS Review. There is a necessity to provide healthcare providers with information about costs and benefits, as well as a determination of acceptable subsidisation.

## BOX 1.1

## The definition of big data

Big data is an overarching term that describes any voluminous amount of data that can be mined for information. Big data has been characterised by the so-called 'three Vs':

- **HIGH VOLUME** — refers to the sheer volume of data collected;
- **HIGH VELOCITY** — refers to the great speed at which data is generated, often in near-real time, and how it can be rapidly accessed, processed and analysed; and
- **HIGH VARIETY** — refers to the many different formats of data and its diverse sources.

Within big data, there is structured, semi-structured and unstructured data. Structured data is characterised by a high degree of organisation. It is commonly text files, displayed in titled columns and rows that can easily be ordered and processed by data mining tools and is readily searchable using simple search operations. It often comprises data contained in databases and spreadsheets. Unstructured data is data that is not organised in this way — such as email messages, word processing files, PDF files, digital images, video, audio and social media posts. Semi-structured data is a cross between structured and unstructured data — for example, emails have the sender, recipient, date, time and other fixed fields added to the unstructured data of the email message.<sup>27</sup>

Big data is almost always digital: it has been created in a computer-mediated environment, and it can be electronically transmitted by the internet and captured and stored in data repositories.



## Health data is generated by a variety of mechanisms in a variety of formats

The healthcare industry generates large amounts of data, driven by record keeping; compliance and regulatory requirements; and patient care. Large amounts of health data have historically been kept in hard copy format, but the current trend is toward digitization of this data. Technology itself is increasing the amounts of data that can be captured. For example, where nurses once recorded vital signs for ICU patients every hour, new ICU monitors and systems can capture vital signs readings in one second increments.

Health data can be created in a number of ways and have a number of sources, including:

- Survey data, from purposive collection of research data in online environments;
- Repurposing of existing clinical research data;
- Data routinely generated from contact with health professionals, hospitalisations, vaccinations, implantable medical devices and social service providers and increasingly through the use of direct-to-consumer services such as pathology and genetic testing services;
- Self-generated *lifelogging* data (including metadata) emitted from mobile phones and other smart devices and appliances, generated through educational and lifestyle applications such as fitness monitoring devices and web based games, gambling, dating and posts on social media;
- Transactional and geospatial data, including data generated from online records of retail purchases and the use of educational and financial services and roads and transport systems, as well as location-sensing devices in public places;
- Administrative and legal data about births, deaths, marriages; credit ratings; criminal convictions; and immigration and customs records; and
- Genetic (single/multiple genes) and genomic (complete genetic material) data.<sup>28</sup>

These data sources include structured and unstructured data. Care providers capture data in both structured forms (eg quantitative observations) and unstructured forms (patient clinical history). This requires electronic health records to enable data to be captured in a structured format and free-text. Free text, however, makes health data more difficult to analyse and integrate.

## Healthcare stakeholders must be engaged on planning for big data

In May 2016, the McKell Institute convened a roundtable with a group of healthcare stakeholders to discuss the importance of big data in health. The stakeholders included private health insurers, patient organisations, the technology sector, pharmaceutical companies, research foundations and a Government health entity.

### Roundtable participants were asked to answer two key questions:

- What are the opportunities for big data to improve health outcomes in Australia?
- What are the challenges?

Participants expressed a range of views on the possibilities that big data in health can bring. They also advised on the role that the government should play in this space.

To take this discussion forward it will be essential to continue to engage and consult with a large number and variety of stakeholders. The Senate Select Committee on Health<sup>29</sup> recently noted that Government papers concerning data and access to data have lacked consultation (for example, the Public Sector Data Management Report<sup>30</sup> and the Australian Government Public Data Policy Statement,<sup>31</sup> both published in December 2015). However the Senate Select Committee on Health appears to have gone to some lengths to consult with and obtain submissions from many stakeholders in its research for its Sixth Interim Report, *Big Health Data, Australia's big potential*.<sup>32</sup> It is recommended that such consultation and engagement must be continued for Australia to realise opportunities for health from big data.



# PART TWO: OPPORTUNITIES FOR BIG DATA TO IMPROVE HEALTHCARE

Researchers, the pharmaceutical industry, healthcare providers, government agencies and consumers identify a range of different ways that big data techniques can significantly improve health policymaking and outcomes through evidenced based decision making. Participants of the McKell Roundtable highlighted the value of using big data to determine the value of healthcare; prioritise high value healthcare; improve medical research and analysis; and develop personalised and targeted healthcare. This section is organised around those benefits.

## Big data can improve the value of healthcare

Big data can help us to better understand and compare the effectiveness of healthcare interventions; and to identify the most clinically relevant and cost-effective ways to diagnose and treat patients.<sup>33</sup>

As noted recently in the *Harvard Business Review*, the ability to use data to measure the value of health (outcomes and costs) will be “the single most important step in improving healthcare. Wherever we see systematic measurement of results in healthcare – no matter what country – we see those results improve”.<sup>34</sup>

### BOX 2.1

## New York’s Medicaid Redesign Team

**The state of New York launched a nine-year programme to improve health outcomes, the efficiency of service delivery and value for money for the state’s six million Medicare beneficiaries in 2011.<sup>35</sup>**

The programme uses big data analytics and linking of databases across primary care, acute care and community health settings to improve the value of healthcare and shift from a traditional payment system to a values based system. (Values based means payment is provided for desired outcomes rather than for standard service delivery).

The Medicaid Redesign Team (MRT) utilised an agile analytics platform using HCI3 grouper technology that integrates a massive dataset across all care settings, covering three years of activity for millions of patients. This allows the New York State to understand the quality and total cost of care and provides a single analytics infrastructure enabling consistent reporting and facilitating sophisticated benchmarking for all.

As a result of the changes made under the MRT strategy, \$17 billion in future expenditures were avoided over a five year period, of which nearly half was reinvested into a reform incentive payment for care providers.



### Big data can help us to prioritise high value healthcare

In Australia there are examples of the provision of healthcare including (i) medicines, (ii) tests and (iii) treatments that are embedded in routine clinical practice that provide little or no benefit and, in some cases, cause greater harm.

#### MEDICINES

Research by Runciman et al (2012)<sup>36</sup> reports that in a study of 1000 Australian adults and their health encounters, only 57 per cent received care considered to be appropriate based on evidence-based clinical guidelines.

Additionally, there are reports of the unnecessary prescription of medications including the prescription of antibiotics for viral infections. In June 2015, the Guardian reported that Australia's consumption of antibiotics is among the highest in the world.<sup>37</sup> According to a study from the Australian Commission on Safety and Quality, 24.4 per cent of antibiotic prescriptions in 2013 were inappropriate.<sup>38</sup> In June 2016, the ABC

reported on concerns that antibiotics are being inappropriately prescribed in up to 20 per cent of cases in Australian nursing homes, prompting fears of the creation of superbugs.<sup>39</sup>

#### TESTS

The MBS Review – Interim Report<sup>40</sup> reports on the increasing number of Medicare pathology tests annually (up from 46 per cent of the population in 2003-04 to 54 per cent in 2013-14). It further reports that the proportion of the population that has an annual diagnostic imaging service has also increased to 37 per cent from 30 per cent in 2003-04, with the number of services per capita increasing from 2.2 to 2.6 during the same time period.

Increasing rates of testing, together with the increasingly sensitive nature of tests is concerning because of the potential for over-diagnosis and over treatment. For example, overuse of routine imaging without a strong evidence base may lead to further unnecessary investigations and may itself cause unnecessary exposure to radiation.<sup>41</sup>

## TREATMENT

Changing definitions that identify larger groups of patients as hypertensive has led to identification and drug treatment of larger populations of patients. Researchers conclude that some patients are being over treated for hypertension<sup>42</sup> despite a lack of evidence that medications can reduce morbidity or mortality in these patients. US estimates suggest this practice may be costing upwards of US\$32 billion a year. Moreover, overemphasis on drug treatment may be inappropriate if it can cause additional adverse effects – such as increased risk of falls – or could be successfully managed by modifying individual lifestyle choices and tackling lifestyle factors at a public health level.

### Big data can identify low value care

Big data provides an opportunity to identify rates of provision of low-value care. A study is currently taking place in New South Wales hospitals that uses big data to identify low value healthcare.<sup>43</sup> The study's lead, Adam Elshaug, is an internationally recognised researcher and policy advisor specializing in reducing waste and optimising value in healthcare. In a paper published in 2012 by Elshaug and others,<sup>44</sup> the researchers use a novel research method for scanning sources to identify existing healthcare services (excluding pharmaceuticals) that have questionable benefit, in order to produce a list of services that warrant further investigation.

Other research recognises methods to identify low value care in hospitals and through primary carers by identifying and measuring the incidence of contraindicated interventions or rates of negative diagnostic tests and screenings.<sup>45</sup> Such measures can assist healthcare providers to be more confident about giving or withholding certain treatments. More evidence-based prioritisation of health funding will also allow more resources to be dedicated to interventions shown to provide the greatest benefit to patients and the community.

Choosing Wisely Australia is a health profession-led initiative that is helping the medical community and patients consider ways to improve quality of healthcare by challenging tests, treatments and procedures where evidence shows they provide no benefit or lead to harm.<sup>46</sup> Choosing Wisely advocates for value-based healthcare solutions, underpinned by the analysis of health data.<sup>47</sup> The MBS Interim Review reports:<sup>48</sup>

*“The Choosing Wisely initiative is a notable clinician-led international campaign aimed at eliminating unnecessary treatments, procedures and tests... Cancer Australia has also commenced a Cancer Statements initiative in the same vein albeit with an oncology-specific focus.”*

### Big data can help to prioritise MBS and PBS items

Australia's Pharmaceutical Benefits Advisory Committee (PBAC) advises which medicines are cost-effective and therefore should be listed and funded by the PBS. For medical interventions, the Medical Services Advisory Committee (MSAC) decides which treatments should be funded under Medicare. This includes new pathology and diagnostic tests, new surgical procedures, as well as reviewing old technologies.<sup>49</sup>

However, there are diverging views as to whether the MBS and PBS are sufficiently underpinned by evidence.

Recent evidence suggests there is a growing concern amongst some stakeholders that MBS and PBS items were funded prior to the introduction of rigorous cost-effectiveness assessment, and it raises the possibility that a “portion of MBS and PBS items do not meet present day clinical and cost effectiveness ‘thresholds’ — and may even cause patient harm — but continue to be used and publicly subsidised.”<sup>50</sup>

The lack of evidence underpinning some items on the MBS and PBS was raised by stakeholders who submitted to the Senate Select Committee on Health:<sup>51</sup>



*"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."*

Better use of real world evidence of the effectiveness and value of PBS and MBS items has the potential to ensure funding for the most appropriate treatments. It may also allow identification of treatments that offer more value than originally estimated. The Senate Community Affairs Committee inquiry into access to cancer medicines also found that data gaps were delaying access to innovative treatments.<sup>52</sup> Linkage of data such as the PBS and MBS would be especially beneficial in treatments for rare conditions and small populations where trials are hard to conduct and "real world" evidence is essential for guiding care.

In 2015 the Medicare Review Taskforce was established to undertake a comprehensive review of the MBS. In its interim report,<sup>53</sup> the Taskforce reported that since Medicare was established there have been significant changes to medical practice. There are MBS items that were considered to be appropriate but are now of less value or obsolete. Some tests and procedures have been identified that are appropriate only in clinically specific circumstances. The Taskforce seeks to identify items that do not reflect contemporary and evidence based practice; inconsistency in the use of MBS items, gaps in access to health service and more general concerns about transparency and ease of use.

The review of the MBS provides a significant opportunity to take information being generated by initiatives such as Choosing Wisely to identify high value care and ensure that these are prioritised. Ongoing reviews and updates of items are also recommended to ensure those items funded and provided to patients are high value and contemporary.

## Big data can improve pharmaceutical research and development

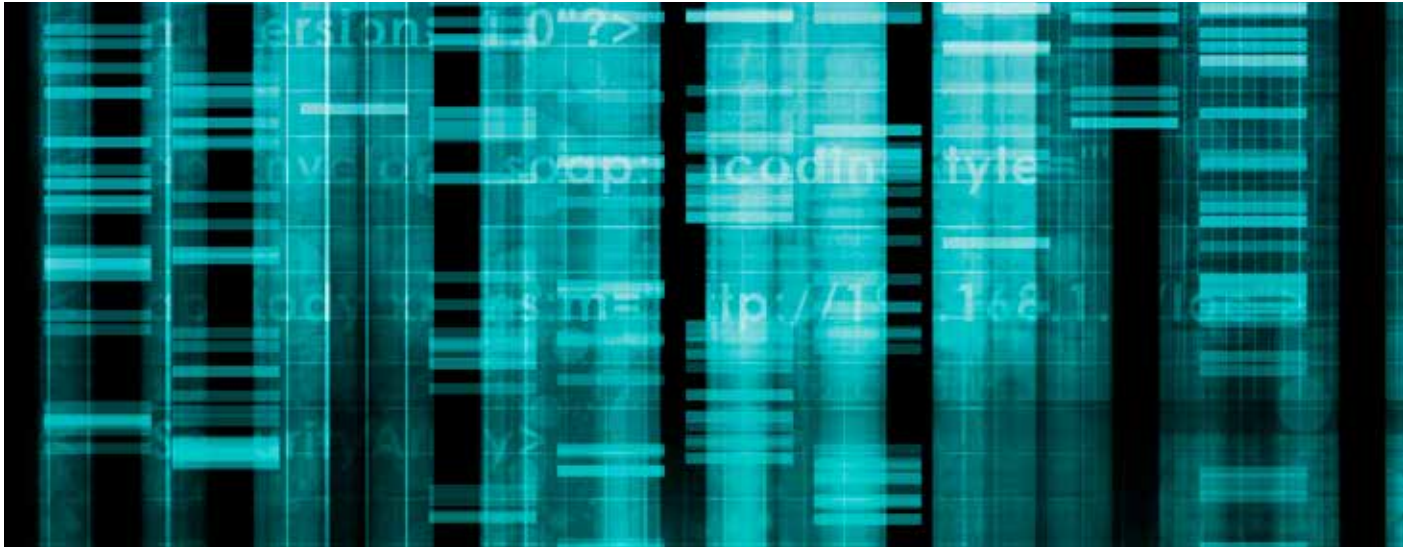
Availability and volume of patient data is key to the success of pharmaceutical R&D. The opportunities for research using public sector datasets include:

### IMPROVING PATIENT SELECTION FOR CLINICAL TRIALS

Electronic health records provide real patient phenotype rich data that can be used to inform clinical trial design and target patient recruitment to better match treatments to individual patients, thus reducing trial failures and speeding new treatments to market.<sup>54</sup> Bringing large volumes of electronic health records together will provide a more representative and complete patient set as single datasets are often found to be incomplete.<sup>55</sup> Finding and enrolling more patients into trials more efficiently will also increase investment.

### HIGH-RESOLUTION OBSERVATIONAL COHORT STUDIES

Linkage of multiple electronic health record data sources permits the creation of large-scale cohorts of patients for whom extensive follow-up data are already available. This allows researchers to answer questions that traditional investigator-led cohort studies cannot - due to the scale, diagnostic resolution, timeframe, or cost. In addition, these data sources make it possible for researchers to define and examine the entire patient journey, from early presentations through various transitions to outcomes. For researchers of coronary diseases for example, this enables them to resolve the time sequence, examine and understand the aetiological and prognostic differences between different coronary disease phenotypes.<sup>56</sup>



### ANALYSING CLINICAL TRIALS AND PATIENT RECORDS IN NEAR REAL TIME

Data sources including electronic health records, clinical trial data and hospital data can be used to make timely contributions to questions of clinical importance.<sup>57</sup> This data together can enable researchers to rapidly analyse clinical trials, and drug impacts to identify follow-on indications and adverse effects. Swift action can avoid significant and potentially costly issues preferably before products reach the market.<sup>58</sup>

### Big data can develop personalised and targeted healthcare

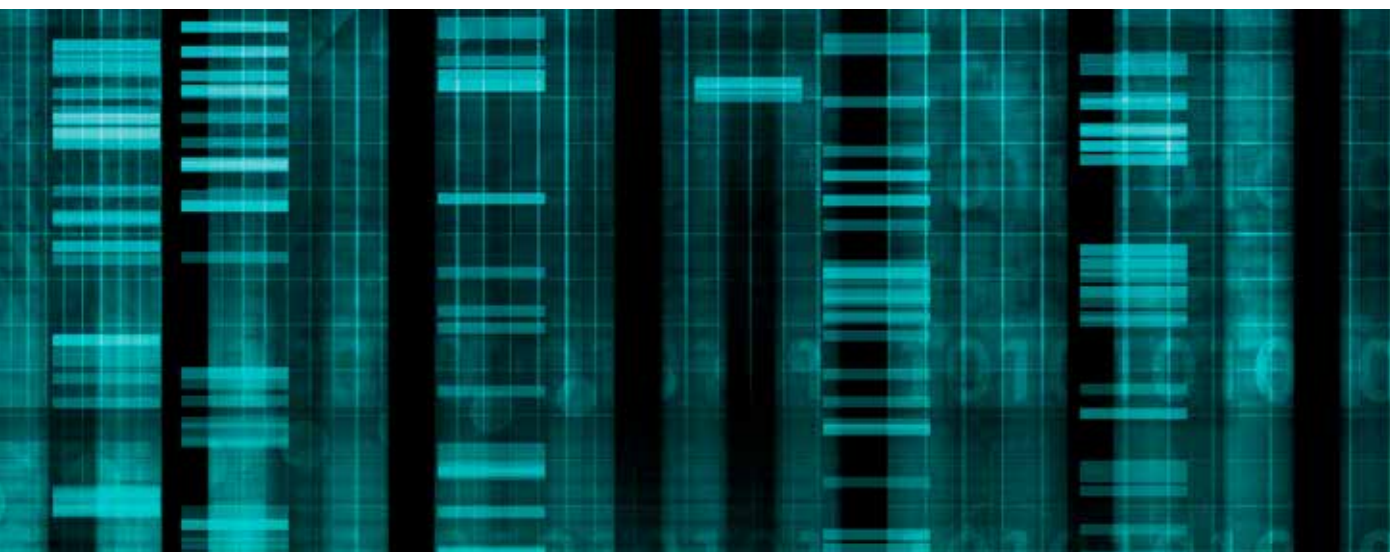
The purpose of 'personalised medicine' is to facilitate clinical decision-making that is predictive, personalised, preventive and participatory. Personalised medicine affords individuals with targeted diagnosis of disease and therapies according to their own profile. Individual profiles can be captured by a variety of data sources including electronic health record, genomic data and personally captured data.

In personalised care a clinician can use a combination of patient history, behaviours and genetic data to identify individualised treatments and drugs. Depending on how this

information is stored and shared the clinician can also potentially compare their patient profile to a databank of similar patient profiles. With this information, clinicians are empowered to make evidence based decisions including to the ability to narrow down appropriate drugs, avoid side effects and adverse reactions; provide more insightful advice on risk prediction and focus on prevention.<sup>59</sup> Accordingly, this approach to medicine is particularly focused on offering consumers an individualised care plan that includes the prescription of the right drug, at the right time, at the right dosage for them.<sup>60</sup>

Smart devices and social media are increasingly important data sources. This technology enables patients to capture their own behavioural data, for example for activities or through patient monitoring devices and to share this as required - leading to much better communication and information sharing between a patient's doctors.

McKinsey & Company has reported<sup>61</sup> how personally captured data through the use of a patient monitoring application can detect when a patient is not using drugs correctly or has changed behaviour in a way that indicated a potential medical emergency. The application collects complex motion data to establish a



base pattern and then looks for deviations that might signal trouble: a sharp drop in activity, for example, might indicate that a patient has stopped taking anti-depressants or has fallen down. Irregular sleep patterns could signal that an anxiety attack is imminent.

The data collected by activity tracking devices is also a potentially useful source of data for health and medical research if it can provide a picture of the levels of activity and exercise of a broad range of Australians on an everyday basis. Three quarters of those Australians using activity tracking devices are willing to provide the data from their devices to researchers, with the proviso that they can't be individually identified. This group amounts to a little over 14 per cent of the entire adult population: that is, about one in seven adult Australians use a fitness tracking device regularly and are prepared to share their data with researchers.<sup>62</sup>

### Big data can improve population health measures

Population health management – and specifically chronic disease management – depend on the ability of providers to identify patients at high risk of developing costly and harmful conditions such as diabetes, heart failure, and chronic kidney disease (CKD).

Personal electronic health record data can help providers develop advanced risk stratification techniques to improve population health management and predictive, personalised care.

The Australian Institute of Health and Welfare<sup>63</sup> suggests that health services planning could be improved with availability of better statistical information on the incidence and prevalence of chronic diseases. In addition,

*“data on comorbidity and treatment—including data on primary care, health service use, medications and whether these are being taken correctly, quality of life, and people's ability to carry out their daily lives—will also help in developing a picture of how chronic diseases affect people in Australia and the effectiveness of strategies.”*

Public sector datasets can be used to analyse disease patterns and track disease outbreaks and transmission to improve public health surveillance and speed response. The McKinsey Global Institute also claims that big data technologies can turn large amounts of data into actionable information that can be used to identify needs, provide services, and predict and prevent crises, especially for the benefit of whole populations.<sup>64</sup>



# PART THREE:

## THE CHALLENGES TO IMPLEMENTING BIG DATA IN HEALTHCARE

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“Data is a game-changer for government. Open data provides the intelligence for insight, invention and exploration that translate into better products and services that improve everyday life and encourage business growth.”<sup>65</sup> **Victor Dominello, 2016.**

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While the opportunities for big data are great and wide ranging, the challenges are also as such. Big data techniques require data to be captured, stored, linked and analysed. But current policy settings in Australia fail to enable the potential benefits identified in Part Two from being realised. Policy settings must be established to address structural, technical, legislative and social challenges. The following section discusses the obstacles facing us in the utilisation of big data to solve some of our greatest health challenges.

### **Challenge 1: Australia's healthcare system is far too fragmented**

Australia's healthcare system is a large, fragmented and complex network of services, providers, recipients and organisational structures provided by public and private sector health services. The Australian, state and territory governments all have a responsibility (which often overlap) for providing services, funding and setting policies. In addition, the private sector provides health services through

private hospitals, medical practices and pharmacies, and additional funding is provided through insurers.

Information in the Australian healthcare system is captured and held by all of these various stakeholders, including:

- (i) Healthcare provider clinical data – captured by individual practitioners, public (state) and private hospitals, and the Federal Government (My Health Record);
- (ii) Administrative claims and cost data – captured by the federal and state governments, private sector providers and insurers;
- (iii) Pharmaceutical and medical products R&D data – captured by pharmaceutical companies and research organisations (public and private); and
- (iv) Personal behaviour data – captured by citizens and commercial organisations.

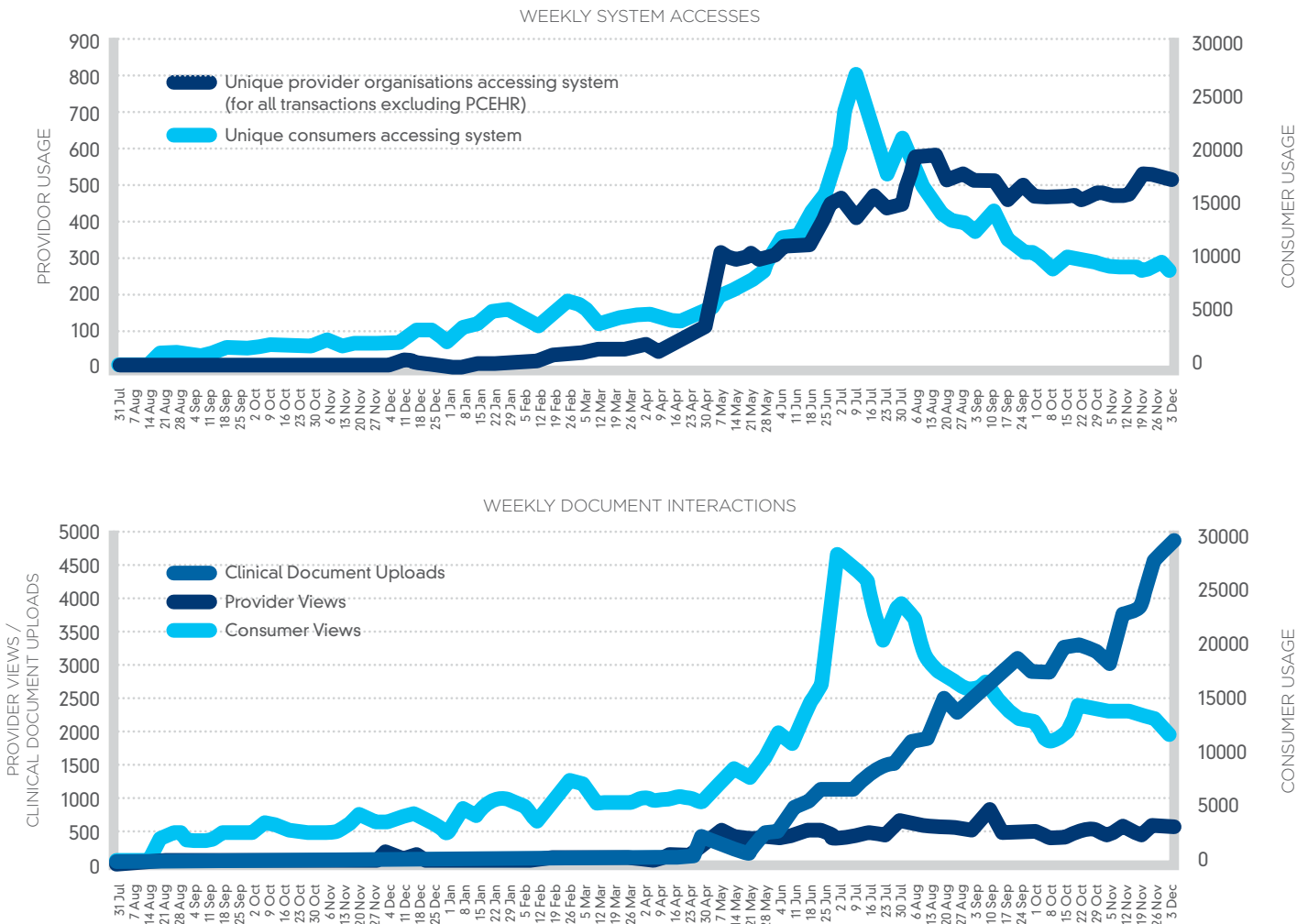
The complexity of Australia's healthcare system together with a fragmented approach to the collection of data<sup>66</sup> make sharing of data difficult.

### Challenge 2: Collection of individuals' data is piecemeal

The benefits of electronic health records are numerous. They improve readability of captured information as well as improve the ability for data to be saved, stored and shared rather than siloed and inaccessible. Without electronic health records, communication between service providers is fragmented, and consumers are compelled to provide the same information to different service providers over and over again, putting a risky over-reliance on memory.

The My Health Record (previously known as the Personally Controlled Electronic Health Record) was launched on 1 July 2012 and gained more than 1 million registered users following a recruitment drive in mid-2013. However, despite continuing consumer registration, adoption and utilisation appeared to plateau in the following months and by November 2013 the Federal Minister for Health, The Hon Peter Dutton MP announced a review of the PCEHR by a small Panel of Health and IT experts.

**FIGURE 3.1**  
Weekly System Accesses for the Personally Controlled Electronic Health Record,  
July 2012-December 2013



Source: Australian Government, Review of the Personally Controlled Electronic Health Record, December 2013

The subsequent report from that review reported that lower levels of utilisation were the consequence of “issues” raised by the stakeholders around the usability and clinical value of the PCEHR. The report made a number of recommendations relating to the governance and operation of the PCEHR including renaming it as the My Health Record (MyHR) and entering into a contract for centralised system operation of the MyHR with the Australian Digital Health Agency, a new entity under the Department of Human Services.

In March 2016, the Australian Government re-launched the My Health Record. It has recently piloted an opt-out system in two Primary Health Networks (PHNs) in North Queensland and the Blue Mountains/ Nepean.

However, the Australian Medical Association (AMA) remains unsupportive of the My Health Record. It regards the My Health Record as not yet fit for purpose.<sup>67</sup> The AMA has indicated that there are several fundamental flaws with its design – including:

- patients are able to remove information from the view of a healthcare provider – without there being a flag to indicate this;
- the shared health summaries are not automatically updated, making them quickly obsolete;
- inaccuracies occur in the upload of data;
- patients should not be relied upon to create their own My Health Record – an opt-out system is recommended.

As a result, there has been little uptake of the My Health Record to date. The Department of Health has reported in a response to questions from the Senate Community Affairs committee, that between 22 October 2015 and 11 February 2016, only 300 Australian GP clinics were using the My Health Record system.

### Challenge 3: Government agencies have issues with capacity, capability and cost

Government agencies face a challenge to develop policy and deliver services for big data. The issues paper developed by the Australian Government’s Department of Finance and De-Regulation – entitled *Big Data Strategies*<sup>68</sup> – identifies the following challenges:

- **Privacy, security and trust** – The use of big data by government agencies introduces an additional level of security and risk that needs to be managed. Big data sources, stored by and shared between government agencies may be the target of hackers. Large structured datasets that are shared between government agencies as part of government policy to make data more open may also be exploited in undesirable ways not currently foreseen. This threat will need to be understood and carefully managed. Australian and state and territory government agencies face the challenge of maintaining the public’s trust in their ability to manage and maintain secure stores and systems for data.

*“The trust that Australians have in these agencies and their ability to securely hold information of a personal nature can easily be affected by leakage of data or information into the public domain.”<sup>69</sup>*

- **Data Management and Sharing** – To facilitate greater use and sharing of data between government agencies requires better transparency of datasets. Individual agencies need to be encouraged to establish and maintain publically available information asset registries.

*“The OAIC (Office of the Australian Information Commissioner), in the paper *Open Public Sector Information – from Principles to Practice*, has highlighted that agencies have identified establishing and maintaining an information asset register as the largest challenge in ensuring more robust information management, and this has been highlighted as a priority action area.”<sup>70</sup>*

○ **Technology and analytical systems –**

Government agencies will need to increase their capability and capacity for storing, sharing and analysing data. This will likely place additional strain on agency ICT systems.

*“Big data initiatives impose large technology overheads in order to meet processing, storage and transportation requirements”<sup>71</sup>*

Agencies will need to consider efficient and secure storage as well as high performance processing platforms. Some agencies will not be able to do this in-house.

- **Skills –** Agencies will need to attract employees with the required skill sets including science, technology, research, statistical, analytical and interpretive skills. They will need to coordinate their work to achieve the desired outcomes.

Furthermore, all of these factors will have cost implications. Storage, security, technology, analytics and skills attainment will require more funding. The desired benefits may not be realised for a considerable period of time later, sometimes for years or decades.

**Challenge 4:  
Australia’s policy settings are overly restrictive and complex**

Big data techniques require that data be made available and usable but Australia’s current policy settings are complex and restrictive. The inadvertent impact of current policy settings means that valuable data such as MBS data are grossly underused<sup>72</sup> and Australia has fallen behind countries such as the United Kingdom and Canada in making administrative health data available to researchers.<sup>73</sup>

Researchers making submissions to the Senate Select Committee<sup>74</sup> on big health data have expressed their concern at the slow pace at which datasets have been made available in Australia. Researchers are severely hampered by an inability to access and use Australian public health datasets.

Professor Philip Clarke, Professor of Health Economics at the University of Melbourne, informed the committee that as a result of the unavailability of Australian public datasets he has been forced to use datasets from Scandinavia and New Zealand for his research.

Professor Sallie-Anne Pearson, Head of the Medicines Policy Research Unit at the Centre for Big Data Research in Health, noted that





data inaccessibility has meant that medicine safety research is not commonly undertaken in Australia. She advised that fewer than 30 studies have examined drug safety in the last 25 years.

*"This needs to change. Australia is actually well-placed to deeply understand our return on PBS investment, and also other health programs. The data already exists. We have information that covers our entire population."*

In relation to data linkage, policy settings restrict who can perform the data linkage function. The Australian Government requires that only certain accredited 'integrating authorities' may link Australian Government data, and for certain datasets legislation exists specifically preventing linkage. The following is a short discussion of the relevant legislation and guidelines that limit data linkage in Australia.

#### LEGISLATION RELATING TO PRIVACY

A number of privacy acts restrict the use of health information or sensitive information. These privacy laws exist at both the federal level (Privacy Act 1988 (Cth)) and at the State and Territory level.

There is an inherent tension between the collection, use and disclosure of health information and privacy laws, which can normally be resolved by using de-identified information. It should be noted that on an issue-by-issue basis, State and Territory laws may also be applicable to individual databases.

The Federal Government has recently introduced a Bill for proposed legislation (the Privacy Amendment [Notifiable Data Breaches] Bill 2016) that will introduce a mandatory data breach notification scheme. The Bill will amend the Privacy Act, and when it comes into force, will apply to all Australian companies currently subject to the Privacy Act. Once the provisions in the Bill become law, Australian companies will, for the first time, have an express obligation to notify both the Office of the Australian Information Commissioner (OAIC) and affected

individuals in the event of an 'eligible data breach' with respect to the information that the company holds on those individuals (subject to certain qualifications and exemptions).

#### SPECIFIC RESTRICTIONS FOR DATASETS – DISCLOSURE AND LINKING

There are a number of pieces of legislation that restrict the matching and analysing of health data. Including:

##### **National Health Act 1953 (Cth) –**

- Officers who obtain Medicare numbers and other health information in the course of their duties, or as a result of being a Pharmaceutical Benefits provider, must not disclose such information in a manner that is likely to enable the identification of the individual without their consent.
- Privacy guidelines (see below) must prevent linkage of information held for the purpose of the Medicare Benefits program and information held for the purpose of the Pharmaceutical Benefits program, unless such information is not stored in a database.

##### **Privacy Guidelines for the Medicare Benefits and Pharmaceutical Benefits Programs (issued under s135AA of the National Health Act 1953)**

- Linking claims information from the Medicare Benefits claims database and the Pharmaceutical Benefits claims database is prohibited except in certain prescribed circumstances.

##### **My Health Records Act 2012 (Cth)**

- Sets out the circumstances in which various entities can collect, use and disclose information for the purpose of including it in the healthcare recipient's My Health Record.
- Generally, health information contained in an individual's My Health Record cannot be collected, used or disclosed except where there is consent, for the purpose of managing the My Health Record system or where reasonably believed to be necessary to lessen or prevent a serious threat to life, health or safety.

### **Guidelines for the Disclosure of Secondary Use Health Information for Statistical Reporting, Research and Analysis 2015**

- Purpose of the guidelines is to minimise the risk of personal information disclosure.
- Data disclosure must comply with legislation and interagency agreements.
- Outlines techniques and provides case studies on ways to anonymise data.
- Sets out guidelines for the use of health information held by signatories to the National Health Information Agreement and excludes data sharing arrangements or data linkage protocols.

### **Challenge 5: The proposed amendments to the Privacy Act 1988 may present technological and compliance challenges**

On 12 October 2016, the Attorney General introduced a Bill to amend the Privacy Act to make it a criminal offence to re-identify, or to counsel, procure, facilitate or encourage the re-identification of de-identified government datasets or to publish or communicate a re-identified dataset. The Bill appears to have been brought about as a result of the recent finding that an anonymised linked data set of MBS and PBS data for 10 per cent of Australia's population (released by the Department of Health) was able to be decrypted to identify healthcare providers.

It appears that there may be a regulatory trend to limit not only the de-identification of relevant information for present or intended purposes, but also to ensure that the relevant information cannot be used to identify individuals. If big data is to achieve its mandate, there must be appropriate legal safeguards against malicious use of data put in place.

The challenge for policymakers will be to find the balance between the competing interests of data security and openness. Where the standards required for de-identification differ across jurisdictions, there will also be challenges for those seeking to comply with applicable laws. Such requirements are also likely to be difficult to meet from a compliance perspective given technological advances that continue to be made in de-identification technology. Another key challenge for policymakers will be in determining the extent to which repeated de-identification (for the same dataset) may be required over time as technology evolves.





# PART FOUR:

## HOW BIG DATA CAN LIVE UP TO EXPECTATIONS

Big data has great potential to improve the quality and reduce the cost of healthcare for all Australians. However, Part Three discussed the various impediments to the realisation of those opportunities at the government and industry levels. The following section provides a series of recommendations that will allow big data to provide more insights, solve more problems, and generally live up to the expectations promised by the increased prevalence of data in our digital and physical worlds.

### The Government must embrace big data

A recent poll by Research Australia<sup>75</sup> found that Australians believe that science improves healthcare; and the single most important thing we can do to improve the health system is to ensure healthcare is based on the best and most recent research. To that end, 91 per cent of the respondents indicated they are willing to contribute their data for research purposes.

People cite various reasons for being willing to share health information for research, including to advance medical research; so healthcare providers can improve patient care; and so that public health officials can better track disease, disability and the causes of disease.<sup>76</sup>

A changing attitude by the Australian Government to the release of data is evidenced by a number of reports and white papers that have recently been released, including:

- Department of the Prime Minister and Cabinet – Public Sector Data Management Report – 3 December 2015.
- Department of the Prime Minister and Cabinet – Public Data Policy Statement – 7 December 2015.
- Productivity Commission – Draft Report, Data Availability and Use – November 2016.
- Senate Select Committee, Sixth Interim Report, Big Health Data, Australia’s Big Potential – May 2016.

What is required is a whole-of-government strategy and framework that shifts away from fragmented and siloed approaches for data, and instead embraces the opportunities of big data. This will require an approach that

- Promotes collection, storing, sharing and linking of data while maintaining privacy;
- Provides a framework for secondary use of health data to benefit research while maintaining the security of data and privacy and rights of all citizens;
- Supports safe use of health information systems; and
- Simplifies relevant legislation.

This report recommends that the Federal Government should conduct an inquiry into the role and future of big data in health as a matter of urgency. The inquiry should put forth a strategy for big data that will guide its collection and usage for the benefit of the Australian population.

### RECOMMENDATION 1:

**The Federal Government should conduct an inquiry into the role and future of big data in health.**

#### We must promote the collection, sharing and linking of datasets

Stakeholders at the McKell Roundtable identified three public sector datasets they believed would improve healthcare and health outcomes should government agencies prioritise them for collection and sharing: (i) the My Health Record (electronic health records) (ii) public hospital performance data, and (iii) public sector administrative health data.

It should be made clear that these datasets should be used within the appropriate secondary use framework and only in de-identified form or with individual patient consent.

#### THE MY HEALTH RECORD SHOULD BE MORE WIDELY USED FOR DATA COLLECTION

Electronic health records provide patients with a single accessible record of care that includes history of conditions, treatments, behaviours and genetics. The advantage of collecting and using these datasets is that they provide a single source of truth, can be shared with providers and provide a conduit between doctors, pharmacists and the hospital system. This single source of data ensures an individual's doctors, specialists and hospital staff can see their health information online from anywhere at any time when they need to, like in an accident or emergency. This will result in better, faster and more efficient care.

Individual patient data, as available through the My Health Record, is also an important resource

for health and medical research.<sup>77</sup> Electronic health records should play part of an important role in the development of personalised and targeted healthcare, the improved design and delivery of medical and drug trials (particularly for high volume drugs prescribed by GPs), and increasingly contribute to research and evidence-based healthcare.

#### INCENTIVES FOR ADOPTION SHOULD BE FURTHER INVESTIGATED

Uptake of the My Health Record must be drastically increased to make it effective. This will be the responsibility of Australian Digital Health Agency (ADHA) which was recently established in July 2016. ADHA will oversee the operation and development of e-health systems, including operating the My Health Record System.

It is recommended that ADHA raise awareness and support the implementation of incentives to promote uptake by GPs and specialists.

The Federal Government is driving adoption through payment incentives. From May 2016 there is a new eligibility requirement for medical practices to contribute electronic health records (referred to by government as "shared health summaries") to the My Health record system for their patients. General medical practices will be required to upload electronic health records for a minimum of 0.5 per cent of the practice's standardised whole patient equivalent (SWPE) to be eligible for the Practice Incentives Programme (PIP) eHealth Incentive payment.<sup>78</sup> This means medical practices will be required to contribute approximately five electronic health records per full time equivalent GP per quarter. The success of this incentive payment must be carefully measured and assessed for its effectiveness.

However, it is the view of the Australian Medical Association (AMA) that it would be more effective to introduce an MBS item and Service Incentive Payment to incentivize GPs to create, share and upload electronic health records. This should be further considered and assessed.

In August 2016, IT Pulse reported<sup>79</sup> that a third of respondents to a survey of healthcare

professionals indicated that despite reservations, they are planning to start using the My Health Record system. For the My Health Record system to work, a far higher proportion of GPs must be using the system, and so we argue for the further investigation of incentives to encourage adoption.

### THE SYSTEM MUST BE EASIER TO USE

Data needs to be accurate, complete and timely if it is to be used to support complex analysis and decision making. Ongoing adoption of the My Health Record system requires a change to operating practices that may have become habitual for GPs and specialists over many years in the profession. Such a change inevitably requires minimisation of disruption to successful operation of a GP or specialist practice and should also deliver value back to the end-user.

Essentially, the benefit of using the My Health Record must be greater than the marginal cost. It needs to be easy to populate with information such as the diagnosis and the primary and secondary symptoms; it must be easy to read and it must be easy to share. For the purpose of big data, it also needs to be easy to analyse.

### NATURAL LANGUAGE PROCESSING SHOULD BE INTRODUCED

The My Health Record would likely entice more practitioners if a capability to capture natural language in the form of typed notes was introduced to the system.

Notes written in natural language could be captured in a more structured form by using a cognitive computing system that interprets a doctor's notes and creates the structured entries automatically, adhering to locally approved clinical terminology taxonomies. In situations where a note contains ambiguity, cognitive analytics would rank all competing interpretations, creating a probabilistic shortlist of options. The user could then be prompted to select the correct option. The power of cognitive computing is to learn from these human corrections, continually refining its logic and predictive algorithms. This will enable data to be captured and searchable in both structured and unstructured forms. It allows

doctors to make notes in a way that is similar to their current practice, it allows them to provide descriptive accounts of a patient and their condition, and does not restrict the record to tick or drop down boxes or pre-set quantitative data.

### GAMIFICATION COULD BE USED TO ENCOURAGE UPTAKE

Gamification of commercial systems is gaining traction over time. It involves the application of science and the psychology of gaming in a non-game context to motivate and reward users to perform certain desired behaviours. It has been proven time and again to be effective at driving behaviour change in a wide variety of use-cases. Common tools in gamification include:

- Point systems to enable the user to see progress;
- Leaderboard comparisons to draw on competitive instincts against peers;
- Team-based reputations to draw on instincts for social belonging and/or reciprocity;
- Portable reputations, to provide users the opportunity to build a long-term asset;
- Tangible rewards, providing a carrot for achieving milestones or exceeding thresholds;
- A 'state of flow', drawing on the optimal state of intrinsic motivation when challenge and skill are well matched.

Getting the design right by drawing on theories of behavioural psychology is incredibly important. A well designed system (policy and tools) will ensure credibility, adoption and sustainability.

## BOX 4.1

## Using games to improve public health

**Pokémon GO took the world by storm in 2016 – the first augmented reality game that succeeded in bringing millions of usually-sedentary gamers into the fresh air and sunlight, and walking kilometres in the search of Pokémon prey.**

Although the app is entertainment, the side effect is exercise, which researchers at the CS Mott Children's Hospital in Michigan, USA, say is getting results for their young patients. The hospital staff use the game to encourage their young patients to connect with one another, push themselves further in their rehabilitation exercises, and to even venture outside.<sup>80</sup>

In Australia, University of Queensland researchers are using gamification techniques to help children with Autism Spectrum Disorder and other social-emotional challenges to learn social and emotion management skills. *The Secret Agent Society* combines a computer game, a board game, child club meetings, parent training sessions and teacher tip sheets to teach children how to recognise emotions in themselves and others; how to express feelings in appropriate ways; how to manage bullying; and how to more effectively interact with their peers.<sup>81</sup>

A recent randomised-controlled trial showed that 76 per cent of children with High-Functioning Autism Spectrum Disorder improved their social skills to within the normal range after participating in the two month program, with the improvements maintained five months after the end of the intervention.<sup>82</sup>





The My Health Record has the potential to be a game-changer in the provision of healthcare in Australia, however, far too few practitioners currently use the system. The Federal Government has recently trialled an opt-out system for the My Health Record in order to encourage greater uptake, however, the Australian Medical Association (AMA) has concerns about the type of information that can be removed from the record by patients. Under the current system, essential clinical information can be removed by patients without signal of the change to warn clinicians. The AMA argues for core clinical information to be retained on the My Health Record in order for the program to work effectively.

This report argues that the Commonwealth Government should undertake a review of the My Health Record with the aim of improving the ease of use, incentives and best practices to encourage greater and wider uptake.

## RECOMMENDATION 2:

**The Federal Government should develop and implement a strategy to promote the collection of individuals' health data through the My Health Record.**

## PUBLIC HOSPITAL PERFORMANCE DATA MUST BE SHARED

There is evidence that in the UK and US public disclosure of performance data is increasingly being used as a tool by funders (mostly government) to stimulate improvements in the efficiency and quality of healthcare.<sup>83</sup> By contrast, there is evidence that valuable hospital data that is collected by Australian, state and territory governments is not released.<sup>84</sup>

The Productivity Commission has observed

*“there do not appear to have been any instances of systematic and detailed cost data being released for individual hospitals (as of April 2015), even though such cost data are already collected for public hospitals on a national basis to inform activity based funding.”<sup>85</sup>*

The Productivity Commission Efficiency in Health Paper suggests the release of hospital performance data benefits healthcare stakeholders by disclosing how health providers are functioning and to identify good and bad practices.<sup>86</sup>

Research by the Sax Institute<sup>87</sup> confirms that releasing more datasets for both public and private hospitals would allow comparisons to be made between hospitals, highlight areas of





good and bad performance, facilitate consumer awareness and ultimately drive improvements. According to that research:

*“There is good evidence that public reporting on organisational providers (hospitals or nursing homes) stimulates quality improvements activities in the clinical areas which are the subject of reporting.”*

And,

*“There is some evidence that public reporting on organisational providers (hospitals or nursing homes) leads to improved clinical outcomes”.*

Hospital datasets are particularly valuable to better understand hospital length of stay; patients who are likely to choose elective surgery; patients who likely will not benefit from surgery; patients at risk of medical complications; or hospital-acquired illness; illness/disease progression; patients at risk for advancement in disease states; causal factors of illness/disease progression; and possible co-morbid conditions. It has been estimated, for example, that about 6.5 per cent of hospital separations result in an adverse event – meaning that those people are harmed (drug reaction, fall or other) while in hospital. Deloitte Access Economics has estimated that if such adverse events or complications are reduced by

even a quarter that would save \$250 million over 170,000 bed days.<sup>88</sup>

It is strongly recommended hospital data should be made easier to access. This will require a review by the Commonwealth, States and Territories to identify data that is captured for hospitals and which of this data should be shared.

### **RECOMMENDATION 3:**

**State and territory governments need to release more hospital data.**

#### **ADMINISTRATIVE HEALTH DATA NEEDS TO BE LINKED**

The barriers to accessing linked data are numerous and include the legal framework, approvals, governance processes and costs. Recently, several papers published by the Australian Government have expressed support for linking of Commonwealth administrative datasets. In particular, MBS and PBS datasets are considered to be highly valuable for the purposes of linking to each other and to other administrative datasets.

It was reported by the Productivity Commission in 2015 that despite efforts to link datasets at the state level, there have been few cases of administrative datasets being linked at the

national level to inform research.<sup>89</sup> Arguments to support the value of linking and releasing MBS and PBS (on a de-identified basis) are made clearly by the Productivity Commission in its *Efficiency in Health* paper<sup>90</sup> which states,

*“Making better use of administrative data held by governments would have substantial benefits. For example, linking PBS data on the pharmaceutical products people use with MBS or hospital data on the medical procedures they receive would help researchers to identify adverse drug reactions or evaluate the impact of medicines on long term health outcomes. Such research can be used to assess the clinical and cost effectiveness of health interventions (in addition to research drawing on clinical trials and other data sources), and thus inform processes to reduce wasteful or unnecessary healthcare. In addition, linking clinical datasets with data on Centrelink benefits would allow researchers to investigate the links between health and employment outcomes over the population. The wealth of data in government repositories would also be invaluable in tracing the impact of government policies and helping to evaluate new policies before they are implemented.”*

The Senate Select Committee on Health<sup>91</sup> also recently reported that while “the Committee is ever mindful of privacy concerns with regard to data, its storage, management, use and security... many submissions indicated that significant health policy development and medical research could be advanced if linked Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) data were more readily accessible”.

In another report, the Senate Community Affairs Committee<sup>92</sup> inquiry into access also acknowledged comments by the Cancer Drugs Alliance that the way to collect data to understand drug effectiveness “is to link existing databases—like Medicare, like PBAC, like the Australian Cancer Database—in a way that protects people’s privacy but allows information that has already been collected and information that can be collected

into a comprehensive picture about what these drugs are doing and what they are not doing.” The committee noted “the importance of effective collection of clinical data and the merit in linking existing databases to enable more comprehensive analysis of the benefits of cancer medicines by the PBAC and clinicians and to support best practice in patient care.”

The Medicare Benefits Schedule Review Taskforce supports more systematic linking of data, particularly MBS and PBS data and especially where it supports clinical and/or research objectives to identify high value healthcare through analysis of long-term trends, modelling of future activity, and the monitoring of individual provider behaviour for compliance purposes. It was noted that linkage of data such as the PBS and MBS would be especially beneficial in treatments for rare conditions and small populations where trials are hard to conduct and “real world” evidence is essential for guiding care.<sup>93</sup>

It is recommended that the Federal Government promotes processes, policies and a review of legislation that facilitate systematic linking of administrative databases for research purposes whilst maintaining privacy and security. In particular there is merit in enabling researchers to link existing databases such as the MBS and PBS with other administrative databases (for example, CentreLink) and other health databases more broadly (for example, the My Health Record and hospital data) to enable more comprehensive analysis of the benefits of medicines; to support best practice in patient care; and to understand patient demographics and needs.

In NSW there is an opportunity to undertake a pilot of linking these valuable datasets through the NSW Data Analytics Centre (DAC) which was established in August 2015. The DAC aims to become a world leader in whole-of-government data analytics, to provide insights into complex policy problems, support greater evidence-based decision-making and improve service delivery for the community.<sup>94</sup> The DAC has initiated a number of priority analytics projects using whole-of-government data. Linking of Commonwealth

and State health datasets is an ideal project for the DAC to pilot. This pilot has the potential to demonstrate how Federal and State health datasets can effectively be linked and identify valuable data insights. One such example could be to link PBS data to hospital admission data to understand individual patient pathways.

#### RECOMMENDATION 4:

**The Council of Australian Governments should immediately undertake an analytics project to link state databases with national datasets.**

#### We need an urgent review of the legislation

The Senate Health Select Committee has made recommendations that clearly have concerns with current inhibiting legislation.<sup>95</sup>

*“The committee recommends that given the changes in technology, and mindful of the capacity and moral obligation for governments to hold and strongly secure personal data and privacy, the government review the operation of section 135AA of the National Health Act 1953, 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.”*

It is recommended that practical reforms of the current privacy regime be developed and legislation harmonised with consideration given to the benefits for releasing data as described in this paper, particularly for research.

#### RECOMMENDATION 5:

**The Commonwealth Government should undertake an urgent review of the legislation inhibiting the collection, linking and sharing of health data.**

#### We must encourage secondary use of health data

The Commonwealth Department of Health was in the process of developing a framework for the secondary use of health information contained in the My Health Record.

A framework for secondary use of data will ideally ensure there is a balance between using personal health information to provide better individual care as well as broader improvements to healthcare and research; and to protect the rights and interests of consumers.

Managing access and use of sensitive data requires the interaction of legal, technical, analytical and, above all, human components to produce a solution. The processes surrounding the way data is collected, handled, utilised and managed by government agencies will need to be aligned with all relevant legislative and regulatory instruments with attention made to making the data available for analysis in a lawful, controlled and meaningful way.<sup>96</sup> Ideally the framework will consider and reflect differences in policies, legislation and regulations between the Commonwealth and the States and Territories.

The framework will preferably provide:

- Guidance on what is secondary medical use, and examples;
- Information collection and management processes and standards;
- Regulatory and governance requirements for secondary medical use;
- Approved secondary use;
- Definition of health data ownership;
- Approved standards of privacy and security (e.g. to achieve de-identification); and
- Access and data release processes and standards.

In relation to providing guidance for trusted access, the Five Safes model (see explanation below) is useful for designing, describing and



evaluating access systems for data, and is used by data providers, data users, and regulators. The model integrates analysis of opportunities, constraints, costs and benefits of different approaches, taking account of the level of data anonymisation, likely users, scope for training, and environment through which data are accessed, and the statistical outputs derived from data use.<sup>97</sup>

The Five Safes model is currently used in a variety of situations in different organisations across the world. The ABS has recently implemented use of the Five Safes model for providing access to the Expanded Analytical Business Longitudinal Database (EABLD) in an effort to improve access arrangements to researchers and government agencies.<sup>98</sup>

The Five Safes comprise:

- 1 Safe people: Can the people be trusted to use the data in an appropriate manner?
- 2 Safe projects: Is the use of the data appropriate?
- 3 Safe settings: Is the environment in which the analysis takes place safe?
- 4 Safe data: Is the data appropriately protected?
- 5 Safe output: Is there a low risk of disclosure in research/analytical outputs?

It is recommended that the framework for secondary use of data refer to and incorporate the Five Safes Model.

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## RECOMMENDATION 6:

**The Commonwealth Government should develop a secondary use framework that incorporates the Five Safes Model of data sharing.**

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### WE NEED TO ADDRESS THE PRIVACY AND SECURITY CONCERNS OF CITIZENS

The value of big data comes from bringing together multiple disparate datasets to identify new patterns and trends and to gain insights.

*“Public trust in government agencies is required before citizens will be able to understand that such linking and analysis can take place while preserving the privacy rights of individuals.”<sup>99</sup>*

Privacy and security policies must be developed through extensive public and stakeholder consultation – in order to ensure a high degree of trust. There is a need for all levels of government to better understand the public's perception and levels of tolerance for sharing data for the purpose of improving their health outcomes.

As noted above, a recent poll by Research Australia<sup>100</sup> indicates Australians are willing to share their data for the purpose of research.

It was also noted by stakeholders at the McKell Roundtable that the privacy rules as currently drafted are quite blunt and don't allow researchers, ethics committees, governments or the community the ability to trade off these issues. This must be balanced with the natural inherent suspicion in the community surrounding corporations using public data. Ultimately there is a need to educate consumers about the pros and cons of strict privacy provisions, involve them in the design process, and design a framework and ways to protect privacy and security to the highest standard while also supporting sharing and linking of data.

#### WE MUST ALSO PROTECT THE SAFETY AND INTEGRITY OF DATA ACROSS MEDIUMS

Patient safety in the use of health data is of paramount concern in healthcare services. Inappropriate use and application of health data has the potential to cause serious harm to patients and to wider health populations.

The larger health service environment – contemporarily recognised as a sociotechnical system – includes technology (e.g., software, hardware), people (for example, clinicians and patients); processes (for example, workflow); organization (for example, capacity, decisions about how health IT is applied, and incentives); and the external environment (for example, regulations and public opinion).<sup>101</sup> It is essential then that health data flows across this complex multifaceted environment safely – starting from its origin as clinical terminology data items, to visual representation for clinicians on computer graphical user interfaces, to be selected accurately by clinicians, interpreted appropriately

by decision support rules, transmitted with integrity across different applications, and to have preserved its clinical knowledge and semantics in both stored and retrieved form. Achieving safety and integrity of health information is a conscious effort from all stakeholders and can only be achieved with a unified, concerted mission by all.

A secondary use framework will ideally define a uniform and clear strategy for achieving safety outcomes. Where possible, legal and obligatory mandates should be applied to developers, users and managers of health information systems in healthcare services. The use of technology-neutral language should also be a key consideration in each instance of the design of relevant legislation moving forward.

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#### RECOMMENDATION 7:

**The Commonwealth Government must design legislation, administrative processes and policies that will simplify the access to health data collections for medical research whilst also maintaining privacy and security.**

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# CONCLUSION

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As our population is ageing and healthcare costs are rising, big data provides us with an opportunity to recalibrate the way we provide healthcare and health services in this country. But rather than just providing us with an opportunity to reduce costs, it also promises to improve the quality of life for all Australians.

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Big data is both an asset and a liability. It provides us with opportunities to significantly improve the lives of all Australians, but it also presents risks: risks of security breaches and risks of being misused. The challenge for policymakers will be to strike the right balance between allowing big data to live up to expectations on the one hand, and protecting the personal information and safety of patients on the other.

This report has laid out the opportunities, challenges, and recommendations for governments to lay the path for big data to fulfill the promises it offers.

But this is also a responsibility for all stakeholders, and all stakeholders must be effectively engaged in the review and policymaking process if big data is to be effectively employed in health. Concerned citizens, healthcare professionals, data experts, researchers and vendors must be involved in developing the framework that will provide the future direction of big data in healthcare in Australia.





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